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ABSTRACT

This study describes how European countries deal with the issues and practicalities surrounding early intervention services. The current situation in relation to early intervention is examined in Austria, Belgium, Denmark, England and Wales, Finland, France, Germany, Greece, Italy, Holland, Norway, Portugal, Spain, Ireland, Luxembourg, Iceland, and Sweden. The report examines the organization and financing of early intervention services and considers the different types of support available in each of the countries. It describes the composition and functions of the teams responsible for early intervention, the participation of families, and the relationship between the education sector and early intervention services. Current developments and areas of concern across Europe are clearly identified and general findings are supplemented by the use of examples. Case studies detail how particular scenarios for early interventions would be handled in the different countries. Results of the study indicate: (1) a wide variety of services exist in the countries, which requires good coordination; (2) among the various services responsible for early intervention, those organized by the health and social affairs authorities are the most common; and (3) education agencies are more actively present in early intervention than in the past. (Contains 12 references.) (CR)

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Early Intervention in Europe

Trends in 17 European Countries

ED 426 557

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Early Intervention in Europe:

Organisation of Services and Support for Children and their Families

Trends in 17 European Countries

September 1998

Editor: Victoria Soriano
European Agency for Development In Special Needs Education

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Preface

This study report describes how different countries deal with the issues and practicalities surrounding early intervention services and support.

The current situation in relation to early intervention is examined in all of the countries participating in the European Agency: the fifteen European Union Member States plus Norway and Iceland.

The subject of early intervention was identified by the participating countries as a key area for investigation by the Agency. This report is the result of a research project completed during the Summer of 1998 - the descriptions and findings refer to the situation in the countries until the end of May 1998.

The strategy adopted for this research involved highlighting the results of previous work in this area and then completing and adding information whenever that proved necessary. This study goes further into aspects which needed more in depth work or had not been covered by previous efforts. This document covers information from all seventeen countries participating in the European Agency. This has not previously been the case, as a more limited number of countries were involved in previous European works.

The report presents general information regarding the situation in each country regarding early intervention services. This general information is supplemented and developed by the use of examples and genuine case studies detailing how particular scenarios for early intervention would be handled in the different countries.

It is felt that the information and findings are of interest not only to the policy makers responsible for early intervention services, but also for practitioners and parents who are closely involved with early intervention work.

The study could not have been completed without the co-operation and collaboration of the Working Partners in the participating countries who submitted country reports and supplied additional information. Gratitude is expressed to them for their assistance in the completion of this study.

Jørgen Greve
Director

September 1998

Introduction

Early intervention constitutes one of the working themes chosen by representatives of the countries participating in the European Agency: the fifteen European Union Member States plus Norway and Iceland. When the Agency first began its work in November 1996, representatives from the different member countries expressed a wish to work more intensively on three themes, which they felt were particularly interesting in the field of special educational needs. These themes were: *Financing of special needs education*, *Teacher Support* and the theme of this document, *Early Intervention*.

Early intervention has already been considered fairly thoroughly in the context of the Helios programme (Third Community Action Programme in favour of disabled persons Helios II, 1993-1996). Two European working groups looked into this theme from quite different standpoints - one was working within the field of education and the other focused upon functional rehabilitation. The documents published by the two groups in 1996 constitute basic references for this study (1) (2). The results of this work and the lines of action they identified were very helpful and no doubt facilitated the drafting of this document.

The existence of this prior documentation, whilst certainly making the job easier, at the same time presented a problem at the outset of the study: how could best use of existing material be made, respecting the results obtained and avoiding unnecessary overlap? At the same time, how could the additional information be optimally obtained via the Agency's partners as was needed?

The strategy adopted was as follows: it was decided to highlight the results of the previous work, to complete and add to whenever that proved necessary and to go further into aspects which needed more in depth work or had not been covered by previous efforts.

This document covers information from the seventeen member countries of the European Agency. This has not previously been the case, as a more limited number of countries were involved in previous European works. It should be pointed out, however, that the type of information received differs from one country to another. In addition, different reference sources of existing information have been used.

Background information, concerning education in compulsory and pre-school education, covers all countries, the main source of information being European official documents in the field of education such as the Eurydice publications.

All countries were asked to verify, complete or elaborate on information concerning the situation and the organisation of early intervention in their respective countries, through the questionnaire developed by the Helios group (appendix 1). The questionnaire was very helpful in obtaining this information, as it facilitated the job of verifying and updating information already collected. At the same time, it served as a starting point to collect information from countries which had not previously participated, such as **Belgium**, **France**, **Ireland**, the **Netherlands**, **Spain**, **Sweden** and the **United Kingdom** (**England** and **Wales**).

The analysis of information from this study does not cover all elements in the questionnaire, but only focuses upon the key points. Analysis was completed with reference to the objectives set out later in this document.

With regards to practice, each country was asked to describe three different situations - called Examples - related to early intervention in practice. Each country contributed with detailed actual cases, comments or observations upon the examples provided.

The first chapter of this study report offers a summary of the main conclusions and reflections arising from previous work. These provide the basic elements that then enables the study to verify the changes which may have taken place, what new elements and factors in this area should be taken into account and what courses of action seem to play an important role at this time.

The second chapter presents a brief look at the relationship between education and early intervention. Some data is provided concerning the total child population and children with special educational needs. The various institutions that take care of

children from birth in the different countries are described, along with information on entry into pre-school education.

The early intervention services that exist in the various countries are analysed in the third chapter. Information on the organisation, composition and financing of services is provided.

The organisation, qualifications and functions of the teams responsible for supporting children are described and analysed in the fourth chapter. This chapter provides a description of teams which are available in the various countries, including an examination of the way they operate whenever the information received for the study made this possible.

The fifth chapter considers the participation of families in early intervention work. The role of families is considered, along with their rights and the support offered to them. Co-operation with professionals is another key element in the chapter.

Information presented in chapters 3, 4 and 5 comes from the questionnaire completed by the Working Partners of the Agency. Some background reference information on the chapter topics is always presented as an introduction to the study data.

The final chapter is partially a summary of the main points emerging from the preceding chapters, but it particularly focuses upon how early intervention is handled in practice. Three examples are described and analysed, showing the measures provided for the child and their family in the various countries.

With all of the elements described above, it is possible to draw out a number of conclusions from across Europe. These conclusions help to identify and underscore key points and results. They also point to new possibilities and new channels for future work, emphasising changes that can be envisaged.

1 Frame of reference

The *concept* of early intervention takes into account two intimately related aspects: the child's age and the action itself. This action can begin at the birth of the child or in the very first years of life - in either case, before the child starts school. This is the concept of early intervention as generally understood and it has been used as the basis for this study and this document.

It must not be forgotten that medical, therapeutic or educational actions and interventions may also be needed later, at anytime in the child's life. This presupposes that effective, efficient means and aids need to be available as soon as they may be necessary. This is a very important aspect from the educational standpoint, as it has to do with making support measures or educational intervention available as soon as a need is reported or identified.

Nevertheless, despite the importance of this aspect, it goes far beyond the scope of this study. It would be worthy of detailed investigation in the future, however.

With regard to the concept of early intervention as an action to be taken within the first years of a child's life, early intervention can be considered as the range of all interventions and measures targeted towards children and their families, to meet the special needs of children who show or risk some degree of developmental delay.

Early intervention aims to encourage and stimulate the sensory-motor, emotional, social and intellectual development of the child in order for them to actively participate in social life in as self-sufficient a way as possible.

This means that it includes any type of intervention needed in the first years of a child's life involving:

- *detection* of problems associated with a physical disability, social, familial or educational deprivation,

- *prevention* of disabilities or further difficulties,
- *stimulation* of development,
- *aid* and *support* to families.

Three main objectives are targeted: *detection*, *prevention* and *stimulation*. Early intervention targets *detection* of disabilities as soon as possible. An early diagnosis, prenatal for example, can mean that various aids, medical, educational or other actions are put in place every time that this may be necessary. The various actions taken will help to reduce the risks to the child or overcome the effects that might follow. This also includes taking into account risk factors associated with the child's social environment which could determine and may affect the child's future development.

Prevention refers to the implementation of measures needed to prevent the emergence of disabilities as far as possible. Two different aspects are covered. The first is the prevention of difficulties before they arise. They are organised particularly in the health field, as well as in the educational field. They basically deal with information and awareness campaigns for the public at large.

The second concern is to prevent the appearance of additional disabilities or difficulties that could be avoided. The early provision of support and care offered to the child may limit problems or reduce the appearance of subsequent problems.

Stimulation emphasises the importance of measures undertaken with children from the time when a disability is detected. It aims to stimulate the child's development from the physical, mental and social standpoints. The idea is to help a child with difficulties as early as possible, given the impact that measures taken in the first years of a child's life will have on their future development. The objective is the promotion of the best possible development of the child by means of medical, educational and social actions, from the moment when a disability is observed, expected or a risk is apparent.

Principle results of work done on the European level

It is difficult to summarise in just a few pages the conclusions that can be drawn from all the work previously undertaken. However, amongst the many aspects which have been studied, the main lines of thought found in the various documents can

be grouped into four categories: *organisation of services*, *team work*, *collaboration with families*, and *qualifications of professionals*.

Organisation of services

Many aspects have been listed in previous documents (1), (2). The most important and those repeated most often are concerned with the organisation of services, their location and management.

Organisation:
Many structures and organisations exist to support the child and the family from every standpoint: medical, psychological, pedagogical and social. This diversity points to the need for co-ordination first and foremost between services, as well as between the various departments involved in early intervention.

Location:
Each child is entitled to receive the support they need, as close to home as possible. This is what is referred to in the documents as accessible services, both from the physical and the economic standpoints. Decentralisation of services makes them more accessible, although there may also exist centralised services, often very specialised, which need to be co-ordinated with each other so that they can act as efficient and effective support.

Management:
It is suggested that a network needs to be established on a national level consisting of services for early intervention functioning at local levels. To improve and ensure quality work, services in charge of co-ordination need to be developed on both local and national levels. These services also need to be responsible for the continuing training of professionals who work in early intervention teams. They could also facilitate the exchange of information and transfer of experience between professionals, as well as act as a support service.

Team work

Very detailed questions have been considered regarding content and diversity of the work to be done and the way teams operate. Here are a few elements worth noting:

Content:
Early intervention is to begin as soon as possible, to prevent secondary disabilities and to improve the effectiveness of rehabilitation at all levels. A global assessment of the child's development needs to be done in the first years of life, to allow early detection of any problem associated with development. This seems to be an important element in preventing risk factors like those associated with unfavourable socio-economic, psychological or educational conditions.

Differentiated diagnoses are needed in order to define the different types of support and treatment to be implemented and subsequently to ensure the provision of the appropriate type of intervention given the child's individual needs. The work needs to be undertaken by adopting a holistic approach, that means the child should be considered as an individual and any decision must take all aspects of his/her environment into consideration.

Medical aspects of a child's developmental profile play a key role, particularly in the case of certain children, but this does not mean that other important psychological, pedagogical and social aspects should be overlooked or forgotten.

The need for quality criteria to be established for early intervention is mentioned. The key concept to be stressed is that the progress of the child and the quality of the intervention work should be ensured at all times.

On this subject, further research needs to be promoted focusing upon the assessment of results, the diagnosis, intervention, guidance, communication between various partners and the means to best promote stimulation in the first stages of a child's development.

Teams:
The diversity of professionals in teams must not have a negative effect upon the quality of intervention given to the child and the family. This is work in which various disciplines must take part and where the duties of each must be well defined and co-ordinated. Co-ordination of teams seems to be a key element. This is also true with regard to continuity support despite possible changes in the team or the services in charge.

Children's access to pre-school settings is to be promoted in order to facilitate the transition to mainstream education as far as possible.

Although the final purpose of the intervention targets helping the child to reinforce aptitudes, independence, social and educational integration, work within and with the family itself is no less important.

Collaboration with families

In the documents, it is clearly stated that parents play a crucial role with regard to their children: they are the child's first point of reference and support. Excluding them from the rehabilitation process or at least considering them as less than active partners means first, losing useful information and second, potentially reducing the effectiveness of the results.

Families need to be supported and informed as soon as a problem arises; this needs to be a continual policy. The idea does not limit intervention with the family to specific moments or crisis situations. It is important to take account of their ideas, their expectations and their needs. Their autonomy is to be respected and their crucial role as parents should be reinforced. This is not easy as parents are often perceived as non-professional competitors. This may also hold true for parents' attitudes with regard to professionals, who can be perceived as rivals in their privileged relationship with their child.

Parental participation is important, as is co-operation with other members of the family including brothers and sisters, grandparents etc.

Professional qualifications

Quite a number of professionals, belonging to different disciplines, may play a role in early intervention teams. Three main conditions are highlighted in the documents as being required for these multi-disciplinary teams to function well:

- a high level of organisation,
- considerable professional expertise,
- flexibility, making the team member attentive to other professionals and families.

Qualifications of professionals are very varied and take account of their range of basic skills. Once the team has been established, continuing training will be necessary. This training needs to include specialised and also general programmes.

Specialised training programmes target specific aspects of early intervention, from medical, psychological or other standpoints and are developed for the professional groups concerned.

General training programmes concern all members of the team and need to cover aspects such as: conditions and dynamics of teamwork, work with families, knowledge of various factors which play an essential role in the child's development.

In the following chapters, the various aspects listed above, in each of the four key categories, will now be considered in detail and complimented with current data from the countries participating in the study.

2 Early intervention and education

The educational system is clearly more and more interested in early intervention. It also participates more and more in the services included in early intervention. The first years of a child's life play a significant role in his/her subsequent performance in school. From this standpoint, an early start, the quality and the relevance of the work done in the first years of the life of a child with disabilities, will affect the educational measures to be taken afterwards.

Providing good stimulation work is logical, since it will reduce difficulties which may be encountered throughout the child's educational career. Added to this is the fact that early intervention often constitutes a more effective preventive measure than the rehabilitation measures which may be necessary later.

Education is also concerned in the sense that a growing range of pre-primary institutions take care of children at a very early age. The different existing provisions might be independent from the educational system, but they often have some direct or indirect links.

It is important to prepare for co-ordinated work with pre-primary institutions in order to ensure continuity with the work already done. The scope of the work done in the field of early intervention must be taken into consideration in order to establish appropriate educational measures when the child joins the educational system.

Some statistics

It is helpful at this point to examine some statistics on children and the young population in Europe. In the **fifteen EU Member States**, plus **Norway** and **Iceland** there were in 1995 (3) more than 147 million people under 30, which represents about 39% of the total population. Amongst these, almost 84 million were identified as pupils and students, which represents about 22% of the total population in the European Union and the two associate countries.

The number of students in compulsory education totals almost 42 million, of which just over 10 million are in pre-primary education.

When specifically examining the statistics for children with special needs, it is more difficult to compile accurate data for the various countries. The difficulties encountered here have to do with the fact that there are differences in the categories of children concerned. To this is the added lack of specific data for this population in some countries. For example, this is the case in **Italy**, where children with special educational needs are integrated into mainstream schools.

However, by and large, the number of children identified as having special needs is between 2 and 12% of the total population of children. This is the accepted range as given in the *Report of the Commission on the progress with regard to the implementation of the policy of school integration in the Member states* (4).

The disparity between these two figures given as the range cut off points, is due to the categories of children included. If children with physical, sensory or mental difficulties only are considered, the estimate is about 2%. This percentage increases when children who have difficulties for familial, social or educational reasons are included.

Two complementary studies analyse this aspect in greater detail. The first of these is by the European Agency (5) and was published in Summer 1998. The second is still underway. It is being undertaken by the OECD with the collaboration of EUROSTAT and UNESCO (6).

Provisions for young children and transition to pre-primary education

In a number countries, children are integrated in the educational system at the age of three or four, as can be seen in the table below. In certain countries, the age is younger. In **Iceland**, for example, children can join the system at one year old. In **France**, schools take in children as from two years old, whilst in **Belgium**, the age is two and a half.

As of the Decree of 25 February 1997 on Primary Education, it was decided that the age of entry into the educational system in the **Flemish Community of**

Belgium would be three years. However, in practice, until some measures are taken concerning child day care, children can still go to the pre-primary school at the age of 2.5 years.

Conversely, we find countries where schooling starts much later: this is the case in **Austria**, **Denmark**, **Germany**, **Finland**, **Norway** and **Sweden** where children are admitted as of six years old.

Table 1 - Age at which children can join the educational system

1 year	Iceland
2 years	France
2.5 years	Belgium
3 years	Italy, Portugal, Spain, United Kingdom (England and Wales)
4 years	Greece, Ireland, Luxembourg, Netherlands
6 years	Austria, Denmark, Germany, Finland, Norway and Sweden

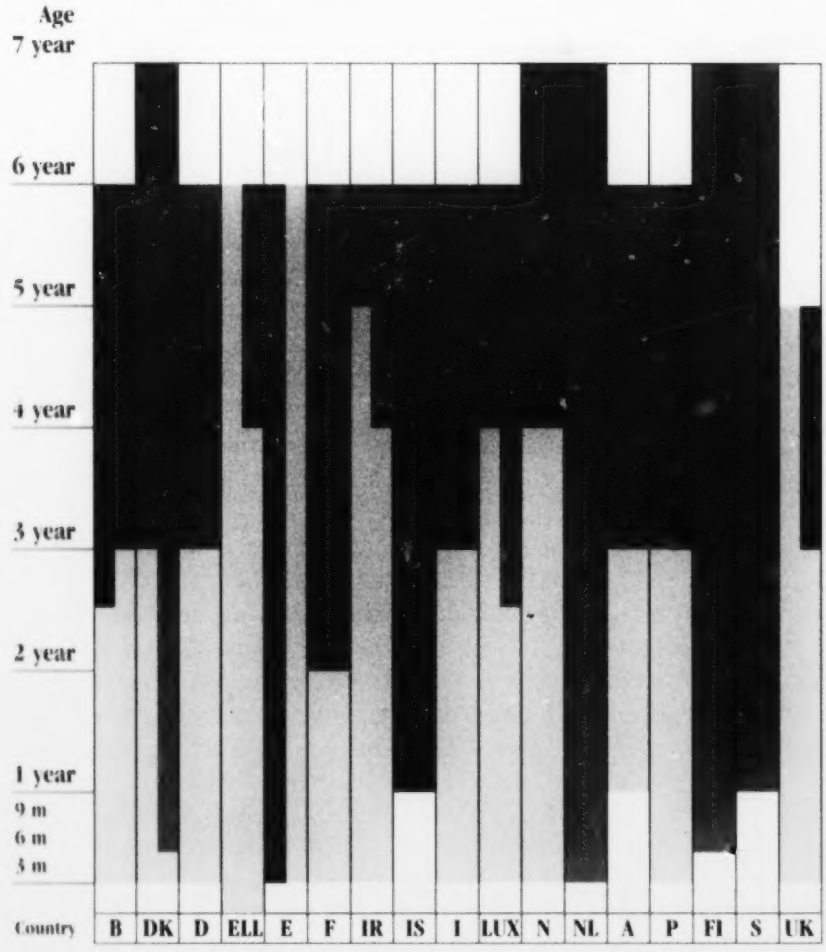
Source: Eurydice and national data

The age at which children join the educational system in turn determines the age at which early intervention services will take place. In most countries, these services take charge of children from birth to the age of three and in a few countries, the children are followed up to the age of six, in close co-operation with the educational system.

Before entering primary school, children can attend various types of institutions. In this document these will be identified as »pre-primary« institutions or centres, covering all kind of provisions necessary for children before attending primary education. These institutions, public or private, accept children from birth in **Greece** and **Norway**, or as of three months old in most countries.

These centres or institutions for infants are quite varied and are not always part of the educational structures within a country. The table below clearly presents the different types of provisions and the ages of children.

Table 2 - Pre-primary institutions



N.B. The countries are listed according to the official name abreviation

Nurseries, Day care, Playgroups

Non school institutions with educational orientation

Schools

Source: Eurydice and national data

On one hand, there are *day care centres* and *play centres*, which are not under the responsibility of the Ministry of Education and whose personnel are not necessarily qualified in education. These centres accept children from birth in **Greece**, or three months in most countries. Children can remain there until two and a half in **Belgium**, or until six in **Greece** or **Spain**. This means that children go straight from there into primary school.

Alongside these day care centres and play centres, there may be *non-school institutions with an educational orientation* which take children from six months old, or three years old in some countries, until the time the children enter primary school. As is the case for day care centres, these non-school institutions gen-erally do not fall under the responsibility of the services in charge of education and, again, their personnel are not necessarily qualified in education. It should be pointed out that in some countries - **Austria**, **Denmark**, **Luxembourg** and **Portugal** - some staff with educational qualifications work in these institutions. In **Finland**, **Norway** and **Sweden** the personnel employed must be educationally qualified. In the last two of these countries, these are the only institutions available for children before they enter primary school.

Finally, there are *schools*. In **Spain**, children can attend them as from three months old. In **Iceland** they are accepted at one year old. Conversely, **Denmark** and **Finland** accept children respectively at six and seven and the other countries as from two or three years old until they enter primary school.

The personnel responsible for the education of children always have a degree in education.

With regards to the choice of pre-primary institutions, parents in most of the countries are entitled to choose the pre-primary centre which suits them the best. Nevertheless, there may be problems when the centres are private or are not located in the region where the family is domiciled. In practice, this choice can also be limited if the centre to which an application is made argues that it does not have the resources the child might need, if it refuses to accept the child, or if there are waiting lists. Waiting lists are mentioned in **Austria**, **Germany**, **Iceland**, the **Netherlands**, **Norway**, **Portugal** and the **United Kingdom (England and Wales)**.

The age at which children enter compulsory education is not the same for children in each of the countries. This age is 4 in **Luxembourg**, 5 in the **Netherlands** and the **United Kingdom (England and Wales)**, 7 in **Denmark**, **Finland** and **Sweden** and 6 in other countries.

In certain countries, children with disabilities are given priority for access to educational centres for pre-primary education, although there are not specific meas-ures provided for them. This is the case in **Iceland**, **Norway**, and the **United Kingdom (England and Wales).** In the **Netherlands**, where compulsory education begins at five, children with disabilities often attend school as from two and a half or three years old.

In **Germany**, the pre-school system is, in some Länder, under the sole responsibility of the Ministry of Social Affairs. From 3 to 6 years children can attend kindergarten and recently they have had a 100% right to a kindergarten place.

In many countries, early acceptance of children in a pre-primary institution underlines the importance of providing good co-ordination between the intervention services and teams and the various pre-primary centres to ensure continuity in the work conducted with children. Continuity of the work should be ensured in order to avoid any gaps due to age or for administrative reasons associated with the services responsible for providing child care. It also means that information and skills will be passed on to the further teams taking charge of the child.

3 Early intervention services

The early intervention services which exist in various European countries were set up on the basis of a number of legal provisions concerning education, health or social services. These provisions stipulate measures on the establishment, organ-isation and role of services as well as on the rights of families. More detailed information on the main legal measures adopted in the various countries can be found at the end of this chapter.

The table below gives a global overview of some main characteristics concerning early intervention services.

Table 3 - Early intervention services

	Legal provisions		Structure		Responsibility		
	Education	Social/ Health	Public	Private	Education	Social/ Health	Local Authorit.
BF		■	■			■	
BNL		■	■	■		■	
DK	■	■	■				■
D	■	■	■	■	■	■	
ELL	■	■	■	■	■	■	
E	■	■	■	■	■	■	
F		■	■		■	■	
IR			■	■		■	
IS	■	■	■	■	■	■	■
I	■	■	■	■		■	
LUX			■	■	■	■	
NL		■	■	■		■	
N	■	■	■				■
A		■	■	■		■	
P	■	■	■	■	■	■	
FIN	■	■	■	■	■	■	■
S	■	■	■				■
UK*	■	■	■	■	■	■	

* England and Wales

N.B. The countries are listed according to their official name abreviation

Organisation and structure of services

The services *responsible* for early intervention vary greatly in all countries involved in this study. They report to different ministries which can pose co-ordination problems. Amongst the various authorities having responsibilities for the management or organisation of these services are: social affairs, health, education and the local authorities.

In the Scandinavian countries - **Denmark**, **Finland**, **Iceland**, **Norway** and **Sweden** - the local authorities are the main body responsible for co-ordinating professional and economic resources intended for children and their families. In most of the other countries, local or regional authorities are also partly responsible for the organisation of early intervention services.

A quite particular situation can be found in **France** where services vary according to the functions to be fulfilled - prevention, assessment or care - and depending upon the responsible authorities.

In **Germany**, all Länder provide ordinary early intervention from one to three years or pre-school intervention. In most of the Länder this is under the responsibility of the Ministry of Social Affairs; in some Länder early intervention, for hearing and visual impaired or blind and deaf children is provided under the responsibility of education through the special educational system.

In **Ireland**, the Regional Health Boards have responsibility for ensuring the delivery and co-ordination of assessment, advisory and support services for pre-school children with disabilities.

In **Portugal**, in most situations, early intervention services are organised by multi-disciplinary teams, comprised of Education, Social Affairs and Health service professionals. Some of these teams can also include the staff of special schools, so as to make use of their special resources. Such teams are developed by means of agreements with the Ministry of Education.

Differences appear concerning the *structure* of the services. These are generally: public services of a local or regional nature; private services handled by various associations; both of these working at the same time.

However it must be observed that most of the services are public at least where medical care is concerned. Other types of measures that could be taken after medical care may be provided within a public or private service context. For example, in **Austria**, medical intervention, treatment and care is covered by the State and by medical insurance companies and is provided in hospitals. Public centres special-ising in sensory disabilities, or private organisations, provide care and treatment other than medical care.

The situation is almost the same in the **Netherlands** where care for children with sensory or mental disabilities is provided by private organisations. In **Ireland,** services are provided directly by the Health Boards or by voluntary agencies funded by the Health Boards.

These organisations play an important role in rehabilitation and in attending to the needs of families. They can be parents' associations in a few countries or various independent local or national organisations. They are often financed in agreement with the social services of the country which may not have direct care services. This is the case of Caritas, or other associations for welfare such as Lebenshilfe, both from **Germany**.

In **Belgium**, early intervention services are approved by the Walloon Agency for the integration of disabled persons in the French Community and by its Flemish equivalent, the Flemish Fund. These services are independent, but must meet a certain number of conditions to be officially recognised. For example, they must have the status of non-profit making organisations.

Another common element in the composition and nature of services in the various countries, focuses upon *decentralisation*. The services or centres are only centralised when they are very specialised.

For example, in **Sweden**, most services are totally decentralised, but children with visual disabilities are supported by a national agency with staff available in each county.

In **Norway**, deaf children are supported by a specialised service operating at national level.

In **Iceland**, if a child has a severe disability the medical team will refer the child and the family to the State Diagnostic and Counselling Centre for the Handicapped.

In **Ireland,** the Health Boards maintain a database of children with specific physical, cognitive, sensory or emotional disabilities. Children with serious visual or hearing impairment are referred to the visual impairment and audiology services of the National Rehabilitation Board and to the Visiting Teacher Service of the Department of Education, which provides a service for pre-school children and their parents.

In general, it can be argued that the teams are organised locally or regionally so that the services are physically accessible to families, meaning that they are close to the family home.

Financing

As has been previously mentioned, early intervention services are generally public, at least for medical care. They take responsibility for economic and professional support to children and their families. This is what is set out in the various legal measures: laws, statutes and decrees.

In some countries, such as **Austria**, **Luxembourg** and the **Netherlands**, the measures are less explicit than in other countries, but this does not prevent children and their families from benefiting from the free services that are provided. In **Luxembourg**, different private services take responsibility for providing support for children at home or at their services' centres after agreements signed by different ministries (Education, Health and Family).

In the case of private services, these are subsidised at least partially by public funds. In these cases, the economic contribution of families is negligible or nothing at all.

One exception should be considered. There are cases where a family decides to adopt a wholly private service, managed by a private organisation, totally independent of public bodies. In such instances, the family would have to bear the full costs of this kind of care.

Legislation on early intervention in the various countries

Austria

- Legal basis of early intervention is laid down by the social legislation of the prov-inces: laws for disabled or laws for income support. Legislation and organisation of early intervention are exclusively reserved to the respective province.

Belgium

Early intervention in **Flanders** is regulated by four statutes:

- The June 27, 1990 Act concerning the organisation of a Flemish Fund for Social Integration of Persons with a Handicap (FFSIPH),
- The June 27, 1990 Decree concerning general conditions for the recognition of services as determined by the June 27, 1990 Act,
- The July 1, 1994 Decree concerning the rules for permission and recognition of services by the FFSIHP,
- The December 17, 1996 Decree concerning the recognition and subsidizing of services for guidance at home.

In the **French Community**:

- Co-ordinated laws of 19 December 1939 on family allowances,
- Decree of 12 July 1990 organising the approval and subsidies to early intervention services for disabled children,
- Royal Decree of 3 May 1991 implementing Articles 47,56,62§3 and 63 of the co-ordinated laws on family allowances and Article 96 of the law of 29 December 1990 on social provisions,
- Walloon Decree of 6 April 1995 on the social integration of disabled persons,
- Decree of 13 April 1995 implementing the decree of 12 July 1990 organising the approval and subsidies to early intervention services for disabled children.

Denmark

- Social Services Act, 1998,
- Primary and Lower Secondary Education Act, 1993.

Finland

- The public Health Act and Decree of Medical Rehabilitation,

- Act of Children's Day Care,
- Comprehensive School Act,
- Act of Social Welfare and Services and Assistance for the Disabled, concerns general provisions for people with any kind of disability at any age.

France
- Law of 30 June 1975 defining guidelines in favour of disabled persons,
- Law of December 1989 on protection and promotion of health, the family and childhood,
- Various laws on de-centralisation which transferred political and financial responsibility for the protection of Motherhood and Childhood to the General Councils Departments.

Germany
- The Basic Law, L001, determines the prerogative of the Federation to enact legislation on child and youth welfare within the framework of public welfare,
- German Federal Social Security Act, articles 39 and 40, up until school age,
- under the Child and Youth Welfare Act, L045, of 26 June 1990, the Länder are required to give concrete form to the general outlines of the law, e.g. on pre-school institutions through their own legislation (L046-L061),
- Child and Youth Welfare Act (KJHG), article 35a and article 27 for additional necessary educational assistance.

Greece
- Law of Education 1566/85 (FEK 167/85), determines special needs education,
- Law of Education 1143/81 (FEK 80/81), determines special needs education, vocational training as well as employment and social welfare for children with special needs,
- Presidential Decree 603/82 (FEK 117/21-9-82), determines organisation and function of special needs education schools and units.

Iceland
- The Act in favour of the disabled persons n. 59/1992,
- The Local authorities Social services Act n. 118/1993,
- Act n. 78/1994, concerning play schools.

Italy
- National Law of Education n.517 (1977),
- National Social Law n.104 (1992),
- different regional laws.

Luxembourg
- There exists a national programme and a plan of action.

The **Netherlands**
- Algemene Wet Bijzondere Ziektekosten (AWBZ), art 6, general law on special health costs,
- Wet Financiering Volksverzekeringen (WFV), providing subsidy to various organisations supporting families,
- Ziekenfondswet, basic law on health insurance that incorporates the funding of the regular child counselling offices.

Norway
- Primary and Lower Secondary Education Act of 13th June 1969,
- The Kindergarten Act of 5th May 1995,
- Social Services Act, aiming to give economical and social security, as well as provide better living circumstances for disabled persons, to contribute to equality and to prevent social problems,
- National Insurance Act, aiming to give the citizens economic security by ensuring income and to give compensation for special heavy expenses caused by unemployment, pregnancy and delivery, being a lone parent, illness and injury, disability.

Portugal
- Law 46/86 of 14th October, Comprehensive Law on the Education System,
- Decree 319/91 of 23 August, which defines the educational situation with regards to supporting pupils with special needs,
- Regulation (Portaria) 611/93 of 29 June, which defines the referral, identification, evaluation and intervention procedures for children with special needs,
- Decree 133/B/97 of 30 May which establishes the several financial subsidies to families,
- Dispatch 105/97 of 1st July, dictates the placement of teachers in pre-primary

centres, in order to support children with special needs,
- Regulation (Portaria) 1102/97 of 3 November, which establishes the financial support to early intervention projects, developed by the Ministry of Education and Special Schools.

Spain
- Law 13/1982 of 7 April on social integration of disabled persons,
- General Law 1/1990 of 3 October on the general organisation of the educational system,
- Royal Decree 696/1995 of 28 April on the organisation of education for pupils with special educational needs.

Sweden
- The Public Health Act and Decree of Medical Rehabilitation,
- Act of Social Welfare and Services and Assistance for the Disabled,
- The Education Act.

United Kingdom (England and Wales)
- The Children Act 1989,
- Education Act 1993 section 175, concerning arrangements for children under the age of two; section 161 and 176, concerning arrangements for children under the age of five,
- Education (Special Educational Needs) Regulations 1994,
- Education (Special Educational Needs) (Information) Regulations 1994,
- Education (Payment for Special Educational Needs Supplies) Regulations 1994,
- The Education Act 1996.

4 Early intervention teams

The teams providing care for children and their families include professionals who belong to very different disciplines. All countries mention the existence of specialised teams who work with very young children and their families from the time of birth to three years old. In a few countries, these teams continue to care for child-ren until they are six, before they enter primary school.

The importance of giving very special support and providing care as quickly as possible, is emphasised everywhere.

In **Belgium**, in the **Flemish Community**, half of the guidance and support activities provided to the population as a whole (children, young people and adults) are adressed to children under six.

A further illustration can be given with the example from **France**. In this country, there are teams for protection of infants ("Protection Maternelle et Infantile") which play a preventive role in the home or in care centres for very young children. These teams focus on prevention and early detection and, in collaboration with other services, establish a medical, psychological, social and pedagogical diagnosis. The results obtained help orient the family in the later choice of schooling for the child. Other teams will then take on responsibility for providing care for the child.

Team composition and qualifications

Composition of these teams is quite diverse in the various countries. The team composition must take account of the needs of the child and his/her family. Teams are described by the countries as having flexible components. Different professionals will join or co-operate with the team depending upon the needs that may be identified. In practice, what determines the number of professionals involved and the skills required is the way these needs are taken into account.

The various countries agree with regard to the main categories of professionals mentioned. They cover four fields: *medical and paramedical*, which take care notably of organic functions and rehabilitation, *psychological* and *educational* fields targeting mental, cognitive and intellectual development, the *social* field, focusing on the child's social environment and the family.

The medical field always has a fundamental role, particularly initially, when an assessment is drawn up before and at birth and also depending on the type of disability. In a few countries it will continue to play a determinant role concerning treatment and educational work. In most countries, the other fields are partners, or totally responsible for the care provided subsequently.

The four fields therefore cover the various aspects of development. They include medical specialists, various professionals in the paramedical sector: physiotherapists, speech therapists, psycho-motor specialists; psychologists, pedagogists, special educators specialised in infants' development having a specific status in certain countries, special education teachers, early years teachers, social workers. Home visitors and health visitors are mainly mentioned in **Scandinavian** countries.

Deaf adults may work with early intervention teams providing care for young children who are deaf or hearing impaired in some **Scandinavian** countries and the **Netherlands**.

This considerable diversity in the teams must not be considered as always the case. This is the maximum overall range of possibilities on the basis of which choices will be made given the needs and resources available. A few countries report a lack of various resources in isolated rural areas. In these cases, it could be that a single specialist may be responsible for providing the support.

With regard to the *qualifications* and training of teams, there appears to be in the countries a trend towards very specific training for this age group, which was not previously the case. Some disciplines have very general basic training, which may require additional training on the work to be done with infants and their families.

Professionals can gain access to these training courses set up by centres or

tutions responsible for permanent training. In most countries, these training programmes are recognised officially and are open to all professionals. In general, these courses are not mandatory, unless they are required by the employer. Professionals also have the possibility of taking courses organised by professional associations. This type of training is not always recognised and in general, tuition must be paid for.

Functioning of teams

The diversity of professionals and disciplines described above, undoubtedly contributes to the quality of the the intervention, but it poses the problem of co-ordination of professionals and teams.

It is clear that the various members of the team must be co-ordinated with each other in order to ensure efficient work without unnecessary repetition of tasks. This is clearer still when there are different teams and services involved at the same time. Very often, families feel lost and tired concerning all the choices to be made, the amount of information they receive and the many courses of action to be taken - all of which could be avoided.

The functions of teams working in early intervention are set down in one of the European documents already mentioned (2). In fact, in all of the different sources of information used in this study, early intervention teams are often called different names, which underlines the diversity of disciplines involved, but results in it being hard to establish the exact meaning of these names: multi-disciplinary, pluri-disciplinary teams and so on.

In this sense it is very interesting to apply the analysis used by Golin and Ducanis (6) which notably takes account of the means of communication and the type of interactions established between the various members. Three types of teams can be identified: *multi-disciplinary teams*, *inter-disciplinary teams*, *trans-disciplinary teams*.

In *multi-disciplinary teams*, the interaction is limited to a simple exchange of information between the team members. Decisions are taken individually and reports are drafted by each of the members. In these teams, meetings focus upon

information regarding the objectives and tasks to be carried out by the various professionals; they can provide considerable expertise and useful information. However, there is a risk of lack of co-ordination, a lack of agreement on decisions to be taken and repetition both in terms of giving and requesting information.

Interactions in *inter-disciplinary teams* are richer. First, the information is shared and co-ordinated. The tasks are accomplished individually in view of the skills of each of the members of the team, but as the information is shared, it is used to complete the work of each member. Decisions are taken as a team, taking into account individual opinions. There is a consistent working programme and interaction between disciplines is possible. In these teams, very often one of the members plays the role of a co-ordinator or facilitator of information. Risks to be avoided include rigidity, which can be due to defending professional opinions with no concessions and the lack of flexibility of the co-ordinator who may direct rather than facilitate exchanges.

Trans-disciplinary teams are the richest in interactions, but the hardest to set up. The information and roles are co-ordinated and shared. They include professionals from various disciplines who do not limit their contribution to their particular competence - they go on to learn from others and to incorporate what they have learned into their own practice. Some tasks may be done by a single member of the group whilst the others act as observers. Results are discussed as a team: everyone is responsible for the objectives and the working programme. A single report is drafted. In these teams, families take an active part. The programme is established by a member of the team with the family, the others are systematically consulted.

In practice, these approaches to team work are not necessarily used on their own, they may be combined. This means that for certain duties a team may work in a multi-disciplinary mode and for others in an inter or trans-disciplinary mode.

In relation to work with parents, the modes identified in the document (2) as being used most frequently are inter-disciplinary or trans-disciplinary. This is also true for co-ordination between services.

Work of teams

Early intervention teams have different functions which target support to, firstly, the child and secondly, his/her family. It is not possible to list and describe everything covered by these two aspects, this would be the subject of a rehabilitation manual. It is necessary to only identify the most significant elements. As was already mentioned, the choice of measures to be taken will depend on the different needs of both the child and the family.

Work with the family constitutes a fundamental element that covers aspects such as information, orientation and guidance, support and training. This area will be developed in greater detail in chapter five.

Work with the child is very complex not only in terms of its content, but also in the way it can be provided. It includes support for the child's global development, preventative measures and educational measures available to aid the transition to the educational system. The various measures of support are chosen so as to reflect the overall care requirements of the child.

These are measures which must be understood from the standpoint of helping the child gain independence - helping the child to help itself. This is an approach that tries to avoid using external programmes that the child and the family resent as something imposed on them and which is quite distant from their interests. According to professionals, the best results can be obtained when the needs and centres of interest of the child and the parents are taken into account. The various methods used at this time in the field of early intervention follow this line. This means that the work must be based on what is possible: aptitudes and capacities, rather than starting with what is impossible: deficiencies.

The various support measures mentioned by professionals from the countries differ. They consider needs, but they will also depend on resources available at local or regional level. Almost every country mentions this.

Four possible support situations are reported. Support can be done at *home*, in *outpatient or day-care clinics*, in *early intervention services* or in *pre-primary settings* (whether day care centres, kindergarten or pre-school centres).

Support at home, particularly for infants, is very common in **Denmark**, **Iceland**, **Luxembourg**, **Norway** and **Sweden**. However, there is a trend towards making it the first option for care in other countries.

In the **Flemish Community** of **Belgium**, for example, the law stipulates that 75% of support is to be at home. In fact the services responsible for early intervention are those providing support and guidance at home.

In the **Netherlands** there appears to be a change in support to children. For a long time they were registered whilst still very young in specialised centres, now however, the strategy is to keep them as long as possible in the family by providing the needed support there.

Support can also be provided by *early intervention services*. This support can be provided in specialised centres for certain types of disabilities. Both early intervention services and *outpatient or day-care clinics*, are located as close as possible to the family home.

Support can also be provided in *pre-primary settings* as is reported by a number of countries. This form of support is particularly emphasised by countries that enrol children in schools at a very early age. In **Iceland**, for example, measures for support can be facilitated in pre-primary centres as from one year old.

In **France**, measures are taken in educational institutions as from the time when the child is two. There are also various organisations that provide support to maintain or integrate children in schools as from three years old.

Other countries which explicitly mention support work in pre-primary centres are **Austria**, **Belgium**, **Denmark**, the **Netherlands**, **Norway**, **Portugal**, **Spain** and the **United Kingdom (England and Wales).**

Support is provided by early intervention teams targeting both the child and the staff working in these centres. This is the beginning of preparation for the transition that will take place in the framework of the countries' educational structures in which the child will be enrolled later on. Early intervention is not initially provided as an integration service, but it is one of the keys for integration in the future.

For the professionals involved, supporting the idea of integration in educational structures is a challenge and means that they may have to review their objectives. This is also true for the professionals working in the educational system.

None of the options mentioned above are exclusive. All combinations are possible depending on the age and needs of children.

The table below gives a global overview of the composition and main types of intervention handled by the early intervention teams.

Table 4 - Early intervention teams

	Compostion			**Support situations**			
	Medic. (M) paramedical (m)	Social	Educational	Home	Out patient clinic/day care clinic	Preprimary settings	Early I. Services
B	**m**	■	■	■		■	■
DK	**m**	■	■	■	■	■	
D	**M**	■	■	■	■		■
ELL	**M,m**	■	■	■	■	■	■
E	**m**	■	■			■	■
F	**M,m**	■	■	■	■		■
IR	**m,M**	■	■	■	■	■	■
IS	**m,M**	■	■	■	■	■	
I	**M**	■	■	■	■	■	
LUX	**M**	■	■	■	■		■
NL	**M**	■	■	■	■		■
N	**m,M**	■	■	■		■	■
A	**M**	■	■	■		■	■
P	**m**	■	■		■	■	■
FIN	**M**	■	■	■		■	■
S	**m,M**	■	■	■	■	■	■
UK*	**m**	■	■	■	■	■	■

*England and Wales

N.B. The countries are listed according to the official name abreviation

5 Work with families

A - Participation of families

General background

Parents have not always been considered as active partners in the educational or rehabilitation process of their children. It was supposed that they would play a rather passive role, as observers of a process centred on their child and as people who would listen to the professionals, not join in debate.

This distance established with regard to the family, which was very often implicit, corresponded to theoretical conceptions focusing on professional skills as the source of know-how on which results depended. The family's role was to aid and forward the work done by professionals.

In recent years, changes have taken place as a result of new ways of thinking and understanding, which places more importance upon the relational process in which all partners involved play a significant role.

The systemic theory - which defends the involvement of families in the entire process affecting the child - considers the family as the basic system for the child's development. With this in mind it gives priority to early intervention as the means to create a base from the emotional, relational and cognitive standpoints, allowing the child's growth and confirmation as a »person« and a social being in all aspects.

The role of families has thus been increasingly taken into consideration and underlined as valuable. The impact of parent associations should not be neglected; they have had considerable influence on changes in attitudes by demanding participation and respect of parents rights.

At this time, the participation of families is a principle recognised and accepted

everywhere with regards to the work to be done during the first years of a child's life, as well as throughout the child's later educational career. This point is stressed in the different documents drafted by the main European and international organisations.

Article 6 of the Standard Rules of the United Nations adopted in December 1993 emphasises the fact that parent associations and organisations of disabled persons should participate at all levels of the educational process. (8)

The UNESCO World Conference held in Salamanca in June 1994 on "Special Needs Education access and quality", declared in the Action Framework that education for these pupils is a job to be done by teachers and parents working together (9).

The OECD Report on Integration published in 1993, mentions that in most countries, parents are recognised as priority partners for the assessment and choice of the school for their children, but in practice professionals do not always respect their rights (10).

The Luxembourg Charter which outlines the results of the work done by the community action programme Helios in the field of education states: "parents, as the prime educators of their children, are key partners in the educational process. They are entitled to choose the education which is best suited to the individual needs of their child." (11).

Nevertheless, at times it is difficult to transpose the concept of participation into practice. There is still a long way to go to reduce the gap which exists between principles and practices.

The role of families

Despite emphasis upon the importance of full participation of parents, they are still at times considered as passive partners who only need to be informed and guided. This is based on a one-way relationship mode, where parents are viewed as if they did not have much to bring and contribute to the support process.

It seems that it is not easy to strike the right balance in participation and to ident-

ify everyone's role. Points of view differ when seen from the standpoint of the family as opposed to that of professionals. Every partner runs the risk of putting him/herself in a key role or considering him/herself as a key part of the process.

There is also another risk to be avoided by both sides: that of replacing others. Professionals who would replace parents by trying to help them too much ("parentalisation of professionals") or parents who would replace professionals because they know their child better ("professionalisation of parents"). What seems to be needed is respect for the needs, expectations, interests and skills of all. It is impossible to suppose that the same point of view will be adopted, because initially personal experience and skills are different and should remain different. To this is added the fact that having to cope with difficult, problematic and even dramatic situations requires great sensitivity and effective communication skills on the part of professionals.

The OECD report mentioned above refers to a very interesting analysis conducted in Northern Ireland on the modes of parental participation in schools (13). Although this is an analysis using the school system as its basic reference, it highlights good elements for reflection which can be applied to other areas of educational concern.

The modes of parents' participation can be grouped into four categories: *marginal*, *consultative*, *participating* and *managerial*.

Marginal participation refers to formal participation taking the form of parent-teacher meetings, open days and occasional visits to the school. Teachers inform parents about the child's progress in school and how to help at home.

Consultative participation goes a little further. It is more frequent, more varied and more informal. Parents are informed by teachers who in turn, are informed by parents on the child's progress, expectations and interests. Meetings may take place at school or at home. Discussions attempt to combine efforts and children can take part.

The *participating* mode is more intense and less formal. Parents can co-operate with teachers in the jobs for which they are competent. They can join the Parent's

Board, go with the children on school trips and undertake activities such as fund raising for the school, for example. Their participation in class activities is nevertheless fairly limited.

Finally, there is *managerial* participation. It concerns a very limited number of parents who take on specific organisational and managerial tasks at the school. In many cases, these tasks are carried out by representatives for other parents.

What is interesting in this analysis is the fact that it underlines the role of parents, which is increasingly active, with regard to information and activities in the school framework. Such a model of increasing involvement of parents can be argued to be applicable to the field of early intervention.

Co-operation with families

Co-operation with families takes account of the fact that they play a fundamental role in the entire educational process of their children. In this way parents are truly involved, as their attitudes and their opinions will have an influence, positive or negative, on the process.

To be really involved implies taking action, being accepted as a full partner and taking part in the decisions concerning the child. It is a question, therefore, of undertaking a co-operative job with the parents who are considered as autonomous, non-dependent partners.

It is clear that this form of participation and the role parents are going to play, will be different given three variables in relation to the child: the age of the child, the level of education in which he/she is involved and the child's needs.

In general, it can be said that parental participation is more intense in the first years of the child's life. It is more manifest in the first levels of education and fades as the child becomes more independent. It is more necessary and permanent when the child has specific needs.

Work with families is too often centred on their needs and is therefore defined in terms of what they require from others, rather than in terms of what they have to

offer. The two aspects are important and must not be neglected as they are complementary and need to go together.

In taking account of what parents can offer professionals, three key functions appear, associated with *information*, *support* and *political pressure*.

Above all, parents are a unique source of *information*. Their privileged relationship with their child enables them to know his/her problems, expectations and feelings better than anyone else. A very young child communicates more readily with parents, in a spontaneous context which is different from that which is created when professional care and support are involved.

Parents will be able to pass on a great deal of information to professionals, who can use it in turn as complementary to their work. This information concerns relationships and exchanges within the family, as well as daily problems and everyday life. This is a source of enrichment for the professional because the amount and the significance of information is much broader.

Parents also have a *support* function, to back up the professionals' work. This includes their participation with therapists in a rehabilitation process, their involvement in methods of stimulation, like Portage, where parents actively take on and plan the jobs to be done with the child at home. This also holds true for the reinforcement parents give to work with deaf children, whatever the means of communication used.

The last function concerns the parents' role as a *pressure* group, particularly in parent associations. This pressure is brought to bear on the authorities and services responsible for education or other sectors, in order to inform them, to express their children's needs and to stand up for their rights. Often what is focussed upon is drawing attention to the realities and problems faced by beneficiaries before measures affecting them directly can be adopted or modified.

In addition, parents at the same time have a supporting role for other parents. Support groups are established to allow an exchange of experience, help and at times, to organise courses for parents.

Concerning the situation in the various European countries, parent associations are present everywhere. They are fairly numerous and may or may not correspond to the different types of disability. Very often, they are confederated at national level. They have similar functions in the various countries:

• *Exchanging information and experience between parents*. This covers, amongst other things, reception and support for new parents ie. those who have just been informed of their children's problems by professionals. In a few countries, the professionals themselves direct parents to the associations.

• *Information and awareness raising*. The focus here is upon informing society as a whole and the authorities and political powers more specifically, about their problems, their difficulties and their needs.

• *Pressure*. Associations try to put pressure on the political authorities by defending the interests and the rights of parents and of their children. Along the same lines, parents can be consulted before any decision is taken on measures that concern them and their children directly.

• *Follow-up*. A few countries, including **Germany**, the **Netherlands** and the **United Kingdom (England and Wales)**, mention the active role played by parents in the follow up of the work done with the child.

• *Research and training*. A few countries point out the role of associations in initiating and promoting research in specific fields or in organising courses. This is the case in **Belgium** and in **Sweden**.

B. Work with families

The work to be done with families covers three fundamental tasks: *information, support and guidance* and *training*.

Information

Information to families constitutes a very important task which needs to be enacted as early as possible. Information must be clear, understandable and complete. It concerns various aspects. It can deal with detected or potential *problems*, their scope, the process to be followed and limits to that process. Any meeting with parents should be well prepared, particularly when it is the first contact and if it is the first time they are informed about the »problem«.

The environment for this meeting needs to be considered: a quiet place, without noise or constant interruptions. This holds as well for any future meetings. The language used is also important: simple, without technical words that are difficult to understand.

In addition to this, there is all the information that concerns parental rights and the *financial aid* against which parents can claim benefits.

The table below gives global information on the different financial support measures given to the child and their family in the different countries.

Table 5 - Financial support available to families

	Family allowances	Tax Reduction	Additonal Costs	Living Conditions	Work Conditions	Other aids	Relief families
B							
DK							
D							
ELL							
E							
F							
IR							
IS							
I							
LUX							
NL							
N							
A							
P							
FIN							
S							
UK*							

*England and Wales

N.B. The countries are listed according to the official name abreviation

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In the various countries, families are entitled to diverse kinds of financial support which are allocated by social or health services. In general, this takes the form of increased *family allowances* to which all families with children are entitled.

The amounts are highly variable depending on the parents' income, but above all depending upon the degree of disability and the degree of independence of the child.

In **Belgium**, for example, an additional complementary amount is granted for the child who has a serious loss of independence. What is assessed in relation to degree of independence is not incapacitation or disabilities, but their consequences.

Financial support can also cover *additional costs* which the parents incur for care of their child. In some countries, this kind of exceptional cost will be borne by the health services or insurance companies, as is the case in **Germany**. Amounts are set by these companies, or by public services given the amount of care the child will need.

Financial aids are also mentioned in several countries for the various expenses incurred as a result of the child's difficulties. This includes technical aids, whether they are used for activities in daily life - mobility, travel, housing - or for the child's education. In **Luxembourg**, for example, parents receive a specific allowance for the child's education during the first four years of his/her life, before the educational services take over.

Other financial aids concern direct economic aid to the family, in this case to one of the parents, who will remain at home to take care of the child after birth for a variable amount of time (up to about two years at most), in relation to the child's need. This is considered a salary or compensation of wages allocated to the parent remaining at home, who maintains his/her social rights as concerns health insurance etc. This is the case in **Denmark**, **Finland**, **Germany**, **Luxembourg**, **Norway** and **Sweden**. In **Iceland** there is a "parent salary" that is intended to cover the extra cost of the child with a disability.

Families in most countries benefit from a *reduction in taxes*. This reduction takes

account of the fact that families with disabled children must generally cope with higher expenses than other families. This tax reduction is related to the disability and is established under the same conditions as those considered for increased family allowances.

For example, in **Greece** or in **Belgium**, the child must have a 67% or 66% (respectively) disability or decrease in physical or mental capacities to benefit from these aids. Official schedules are set by the Ministries of Health or Social Affairs using fixed criteria which take account of the physical or mental disability affecting the child.

Finally, there are advantages given to parents in relation to their *living* and *working conditions*. In **Italy**, for example, the family benefits from reductions on public transportation and is given priority for allocation of a council house. The parents also are entitled to three paid non-work days per month. If the parents work in the public sector, they are given priority in the choice of workplace, so as to be as close as possible to the home; they also have priority for transfers in the workplace.

Issues concerning *relief families* are discussed below.

Support and guidance

Support covers different areas of action: *psychological*, *educational*, *social*, *practical* and *technical*.

The first concern is *psychological* support at the request of the families. This type of support fundamentally attempts to help the families accept the child's problems, reducing their own and their child's frustrations and attempting to avoid the isolation that often surrounds them as parents. A few countries mention the fact that early intervention services organise this kind of support with parents, in groups or individually.

Support and *educational* orientation are also mentioned. These two aspects will enable the parents to act as co-therapists in implementing various intervention programmes at home.

From the *social* point of view, this support targets the family's living conditions, the aids they need and triggering the administrative and legal formalities which will enable the family to obtain the financial and professional aids to which they are entitled.

There is also a question of *practical* support in learning how to carry out daily domestic activities to which the family is not accustomed, but feels it should learn to do. This support can be provided for a limited time, until the parents feel more reassured, less anxious about all the changes, responsibilities and new tasks and until they can cope. However, it can also be more permanent if the child's needs are greater.

Technical support is in direct relation to the other types described above. Here, parents learn to use technical aids such as hearing aids.

One last element to be mentioned is that of *relief families*. This is a type of support offered to families by public or private services. It does not exist in all countries, but it is a service increasingly in demand, particularly in the case of families with seriously disabled children. Relief families are carefully chosen, who are not related to the child's family and who take him/her in for a certain amount of time. This can be one day, one week, a weekend, to give the parents a rest, to let them be alone together or to concentrate on other brothers or sisters.

This is common practice in **Denmark**, the **Netherlands**, **Norway** and **Sweden**. At times, for specific situations it is possible in **France**, **Germany**, **Iceland**, **Italy** and **Luxembourg**. This possibility also exists in the **United Kingdom (England and Wales)**, but in practice, will depend on available resources.

Other schemes are also evident: they target the same thing - taking some of the load off the parents. In some countries, it may be the case that children are placed with a host family for a short period. It can also entail having various organisations take charge of the child at holiday time that offer a variety of activities.

Support and guidance concern daily activities, personal guidance addressed to the parents and also contact with other parents who will understand their problems and their feelings better than anyone else and with whom they can share their experience.

Training

Parental education considers parents as trainers in the broadest sense of the word. They can be given help in developing their skills. The child's development will be better facilitated if the parents feel good about the educational process and their relationship to it.

Training is proposed in a number of countries, but it is organised and delivered in very varied ways and is not always considered a priority. Very often, private organisations, parents or other associations, may take on this responsibility. It can be systematic, once the child's problem has been detected, or occasional, relying particularly upon application from the family.

By and large the training is done by professionals for the parents. Far more rare are training programmes which bring both parents and professionals together at the same time. This is however the case in **Luxembourg** - no courses are scheduled for parents, but they can attend courses organised for professionals.

Generally, training is intended for the parents and less frequently for other members of the family. Other family members are apparently increasingly desirous to take part.

6 Examples

Rationale

This chapter will attempt to present a portrait of three different, actual situations which families and their children may have to face. The data for these three analyses, is based mainly on real examples provided by early intervention professionals in thirteen European countries. The countries which were not able to contribute detailed examples had the opportunity to add comments in order to describe their situation in comparison to the other countries.

The initial idea for the study was to create a standard example based on the information collected from all of the countries. However, the diversity evident across European countries did not allow for this, at least not in the way anticipated. Despite the many elements in common, there is a great variation in resources and options, which need to be underlined and respected. In fact this diversity give us greater insights into the strengths and weaknesses of certain early intervention strategies, used both within and between countries.

In as broad a manner as possible, the examples describe three quite different situations associated with a physical disability, a mental disability and a sensory disability. The age of children is also taken into consideration. It will be used to underline the different types of action included in the early intervention context, given the age of the child and the increasingly close ties with educational services. The socio-economic level of the family and the environment will be considered as they seem to play a role as well, both in relation to the measures and the results.

Each of the three examples described below will present: the various *financial measures* provided to the child and the family; the *organisation of early intervention services* caring for the child and the family and the different *types of support* made available to them in the various countries. In this way it is possible to see how the different elements described in previous chapters are implemented in

practice. It should be stressed however, that these examples do not attempt to represent any national situation.

To avoid unnecessary overlap, the elements which the various countries have in common are considered globally at the very beginning for each of the three key aspects considered. References for individual countries focus upon specific, noteworthy elements.

Each example has one or two complete case studies linked to it (5 in total), in order to better illustrate practice from different perspectives and present quite different national situations. These can be found in appendix 2.

Example A: A new born baby with brain injury in an average social-economic group family living in an urban environment

Different types of aids and measures existing for the child and his/her family

A's problems were identified at birth. The hospital will certify to the child's problems at birth. This certification, which is in the form of a report or diagnosis, will be the point of departure for any subsequent application of the family for financial aids. The application will be addressed to the corresponding services. The care given to the child and the aids benefiting him/her and his/her family are free of charge, but correspond to different departments and cover different aspects and the steps to be taken are different as well.

These will be more or less complex from one country to another. *A*'s parents will find it easier to understand what to do in some countries, which have established co-ordination services providing fundamental aid for parents.

One of the first pieces of information they will receive will be provided by the hospital or health services. It concerns financial aids to which they are entitled. The formalities to be completed and the conditions for obtaining them will vary somewhat from one country to the next. Other types of information will follow relating to the services and arrangements available for the child, and the potential organisation of their life in the future.

In the first instance, *A*'s parents will be entitled to additional family allowances. If they live in **Belgium** their allowances will be increased at the time the child's disability is recognised by more than 66%. They will also be entitled to a childbirth allowance and health insurance will pay for all medical costs. The family will benefit from other social advantages such as a reduction in taxes (a disabled child counts for two dependants), a reduction of a mortgage loan, a reduction of VAT on the purchase of a vehicle (6%), a reduction of gas and electricity if the child is recognised as 66% disabled. If the mother is on salary, she will be entitled to 15 weeks holiday, including 8 mandatory weeks immediately after the birth. If the mother has an employment contract, she will receive 82% of her salary, if she is unemployed, she will receive 60% of the usual unemployment allowance plus an

additional allowance of 19%.

In **France**, after an application and review of the dossier, the family can be allocated a special education grant.

In **Germany** all care and support to parents will be free of charge. Physiotherapy for example is covered by the medical insurance. In some Länder, Rehabilitation is done by the personnel from the special educational system and the cost is born by the local social services; this is also true for support given to parents. The centre which is responsible for early intervention covers all other expenses (in the case of *A*, an organisation managed by the Protestant church).

In **Greece**, parents must apply to the Ministry of Health and Social Affairs to receive the subsidies to which they are entitled. These will be granted once the child has been assessed by the competent services.

In **Italy**, the National Health Service must cover all medical costs of the child's treatment. Support will be provided by the same services and by those organised by the local authorities.

In **Luxembourg**, once the hospital has assessed the child's problems, he or she will be referred to the Social Security. The parents then will be informed of their rights: double family allowances, an increasing number of free days, tax reduction.

In **Norway**, once the hospital has drawn up a certificate relating to the child's problems, a report is submitted to the Social Security Bureau for an extension of maternity leave as long as the child remains under medical attendance. A social worker from the same Bureau informs and helps the family lodge applications for standard benefits and for supplementary benefits to which they are entitled. These supplementary benefits, in four rates, are provided for children under 18 with special needs and who require supervision and care associated with an illness or a disability. The standard basic benefits (in five rates) cover any extra cost associated with a disability. *A*'s family will be entitled to type 2 additional benefits for two years.

As the child is often ill, parents will be entitled to prolonged maternity leave. In any case, until the child is 15, the parents can benefit from 40 welfare payment days

per year: 20 for each member of the couple or 40 for one of them. Once the child is a bit older, technical aids are called for; they will be financed by the Social Security Office and supplied by the county Aid for the Disabled Distribution Centre. The law provides that the different types of equipment needed will be made available. In *A*'s case the child can have three special chairs later on: one in the house, one in the pre-school, and one in the host family.

In **Portugal**, a multi-disciplinary team gives support to the family and the child. A social worker will inform the parents on the support that they can obtain for adaptations, transport or other purposes. Contacts will also be made with the Social Services and the local authorities.

In **Spain**, all care and support provided will be covered initially by health services and subsequently by services reporting to social affairs and education. The social services responsible for disabled persons (Imserso) are the only authorities entitled to officially recognise the degree of disability of the child; this recognition in the form of a percentage will determine the level of aid granted.

In **Sweden**, the place of residence and income do not have any influence on the allowances and support from which the family can benefit. Once a child is born and problems have been detected, both parents will be entitled to extended, unlimited maternity leave - they can stay together and take care of the child. They benefit from increased family allowances independently of their income.

Organisation of early intervention

From birth, *A* is taken in hand by the hospital in order to continue the necessary care. This hospitalisation lasts a certain amount of time, more or less given the child's difficulties. Hospital care proves necessary several times in the first year of the child's life and even afterwards given his/her fragile state of health.

A's parents are informed about the pathways and possibilities to be followed after *A* is released from the hospital.

Although the intervention corresponds to a fairly similar model in the various countries, differences appear with regard to guidance procedures, the facilitation

of steps to be taken and the preparation for returning home.

In **Austria**, the hospital neuro-paediatrician makes the first diagnosis and the hospital refers the family for early intervention via one of the institutions that provides this care.

In **Belgium (Flemish Community)**, ***A***'s parents get in touch with a centre specialised in developmental problems ("centrum voor ontwikkelingsstoornissen"). This centre facilitates the provision of care by an early intervention centre, which contacts the family one week later. *(More information regarding this example situation in the Belgian Flemish community, is available in the case study given in appendix 2).*

In the **French Community**, the personnel at the maternity ward orients the family to the early intervention services. Contacts take place in order to establish a contract of collaboration and the actions to be undertaken are scheduled.

In **Finland**, the hospital provides the care initially and then in turn, the support centre for children, which is part of the local health services, continues the rehabilitation.

In **France**, if ***A***'s problems are very significant, he/she is hospitalised at birth for additional examinations in a paediatric ward or a paediatric-psychiatric ward. Different alternatives are possible at this point: the child will be placed in a live-in centre for the multiple-disabled and severally mentally handicapped; he/she will continue to live at home and will be followed by an Early Treatment Medical-Social Centre which will provide ambulatory care and rehabilitation of the child; he/she can be enrolled in a specialised day care centre and be followed by the same service.

In **Germany**, the hospital takes care of the child from birth and gives the health and medical treatment he/she needs. At the age of eight months, the child and his family will be supported by a local early intervention service.

In **Greece**, parents contact a specialised team at local level that helps them with the practical steps. Afterwards they contact child care centres that work with edu-

cational-medical centres. The family applies to the medical authorities for any health care aids. The child is accepted in the child care centre at birth, the cost being met by the local authorities, which will provide all necessary support via these services.

In **Luxembourg**, the **Netherlands** and in the **United Kingdom (England and Wales)**, the situation is quite similar. ***A*** remains for some time at the hospital where he/she begins the early intervention treatment. As soon as he/she returns home, the intervention is done at home by a team reporting to a medical organisation (a hospital or functional rehabilitation centre).

In **Norway**, ***A*** remains at the hospital long enough to receive the necessary medical care until the child is transferred to the paediatric service where the rehabilitation work begins. A rehabilitation team takes charge of the family and prepares the return home. This team exists in each county; its job is to meet the needs of disabled children and adults. It reports to the county health service. To prepare the return, the team organises an information meeting with representatives of the health centre, including an advisor for the disabled and a physiotherapist for the child. The purpose is to inform parents about local resources and about the support they will need in the future.

Once the child is home, the health visitor proposes to form a group of professionals reporting to various local authorities which will assist and monitor the family. This group includes the health visitor, who co-ordinates the measures to be taken and visits the family regularly; a specialised teacher from the Psycho-Pedagogical Service (PPS "PP-tjenesten"), responsible for all pedagogical measures, a social worker from the Social Security Office, a doctor from the health service, a physiotherapist for children and the child's parents.

In **Portugal**, the infant care departments in hospitals and childbirth clinics will handle immediate problems after the birth with their own personnel. If there is neurological damage, ***A*** is referred to a centre specialised in cerebral palsy after a meeting at the hospital. This centre then takes charge of the child and the family. The family is informed of its rights and various benefits. Contacts are established with other services and local authorities for the required support and for future access to a child care centre (at about two years).

In **Spain**, the hospital cares for the child for a certain amount of time in the ward for new born babies. Then the social services of the municipality take over to assist the family if their economic or housing conditions are poor. These services then direct ***A*** to a local early intervention service. This service gets in contact with those which have previously provided care for the child and his/her family: the hospital for medical care, local social services for support to the family, the infant school (for very young children) which will take in the child a few months later, the social services for the disabled (Imserso) for official recognition of the disability with the right to benefits that comes with it and care and treatment once the disability is recognised.

In **Sweden**, again a hospital team will care for ***A*** and support the parents. The hospital sends a letter of introduction to the county centres which handle rehabilitation of children. Someone from the centre gets in touch with the family and subsequently offers support.

Support to the child and the family

The intervention continues when ***A*** gets home. The early intervention team goes ahead with various follow-up and support measures that have already been initiated. It can be said that they target the most important needs of the child and the family. Consequently, they target the child's overall stimulation and development given his/her difficulties and the adaptation of the family to the new situation.

If the problem of survival is a major one initially, the parents must now accept an unexpected situation for which they were not prepared. Psychological and social support will be of major importance, because at times ***A***'s mother handles the situation better than the father which may cause tension between the couple.

The living conditions and where the family lives can also be important. Adjustments are necessary and applications must be made to social services. Living in a city where all the services are available at the hospital will no doubt facilitate the parents' efforts to obtain the necessary care and aids, without planning numerous trips or more complicated arrangements.

The early intervention teams will play a key role in support, follow-up and co-ordi-

nation. Professional work with *A* and the family will be provided in slightly different ways according to the countries.

In **Belgium (French Community)**, a child care specialist follows the child in the maternity ward, a psychologist and an educational specialist from the support services, handle activities to stimulate the child. In the **Flemish Community**, a remedial educationalist and a physiotherapist in the early intervention centre go to the home to talk about problems at the time of birth and (more particularly) the parents' feelings and about what the child is able to do. Observations are made in order to estimate his/her future development possibilities and what stimulation is appropriate. An explanation is given to the parents of the activities of the centre. A decision is taken that once a week someone will come to the house to visit the mother, who is the one who essentially takes care of the child. The father has problems in accepting *A*'s situation. The two professionals decide, each in his/her own field, on the kind of support to be set up, trying to involve the mother as much as possible. The family situation must be carefully considered: there are other children and the father keeps his distance concerning the problem.

After a few months, a private physiotherapist comes to the house three times a week to increase the frequency of the therapy sessions (Bobath in this case).

The centre continues to follow the case, by co-ordinating all interventions, following the child's development, and continuing to support the family and particularly the mother. After a certain time (at about 18 months), the opinion of a speech therapist will be requested on problems concerning feeding the child and oral communication. When *A* goes to school - probably a special school - the role of the early intervention centre is over. Nevertheless there will be sporadic contacts at the request of the family and/or school.

In **Finland**, a rehabilitation programme is established at the outset and is regularly monitored and assessed. Three aspects are covered by this programme: medical, social and educational rehabilitation. The first is done by the hospital or health centre and concerns the various therapies (for example physiotherapy). The health centre takes charge of the child and the family once the medical tests have been done in the hospital and continues the rehabilitation. From a social point of view, it concerns any adaptation needed in the house, leisure or other situations.

In **Germany**, ***A*** will have physiotherapy sessions once a week at home. He/she will also have a rehabilitation treatment for feeding, social and emotional development once every two weeks. Later, all these treatments will be given at the early intervention centre. The child also does aqua-therapy once a week.

With regard to parents, they will be given support and assistance for six months from a social worker qualified in this field. This professional will stay at ***A***'s home 5 hours a day to help the parents take on the new practical duties, to guide and help them.

The various professionals in the early intervention centre - physiotherapist, specialised teacher, psychologist and speech therapist - work together in a closely-knit team. At least every four months, the programme is reviewed in light of the child's progress. The technical aids that ***A*** will need are supplied later by a specialised centre.

In **Luxembourg**, the early intervention team will advise and will be responsible for supporting the family. ***A*** could benefit from placements during some weekends if needed.

In **Norway**, the child's rehabilitation begins in the hospital with a team which also assists the parents. A psychologist and a social worker talk to the parents and try to help them cope with their new situation. The team responsible for the rehabilitation reports to the local health services; they provide direct care and services and complete diagnoses. Various professionals work there: a specialised doctor, a specialised teacher, a social worker, a social nurse, a physiotherapist, a psychologist, an assistant nurse etc.

A few days after returning home, the health visitor and the physiotherapist will come for a visit. This health visitor will propose creating a follow-up group, that he/she co-ordinates. The Psycho-Pedagogical service will be part of this group, represented by the specialised teacher who will go in this case to the home twice a month to stimulate the child, in collaboration with the physiotherapist and the parents. A working programme is established which will be carried out by the parents.

Relief periods will be envisaged and applied for via the health visitor, given the load of work that ***A*** represents for his/her parents. The purpose is to help maintain a good atmosphere in the home and to allow the family to take part in various social activities. ***A***'s parents will benefit from 40 hours relief periods per month that they can use as they please. The counsellor for the disabled will look for a trustworthy person to take over from the family during these relief periods.

At the time when ***A*** is nearing his/her first birthday, the parents will choose between different options: unpaid maternity leave, unpaid reduction of working hours, enrolment in kindergarten, enrolment and reduction of working hours. The kindergarten chosen is not very near the home, but seems to present good environmental conditions for the child. Children with disabilities have priority for enrolment in kindergarten, if the person following the child considers this desirable. A 10% subsidy for these pre-schools is intended to take the necessary measures for disabled children. In the case of ***A***, this additional amount will be used for a support teacher who will help the child in collaboration with the other professionals.

In **Spain**, the early intervention centre is the only service responsible for following ***A*** and his/her family and will take care of co-ordination with other services which may play a role: health, social services, education. In fact, the main role of the team at the centre will be to prepare the child's entrance in the educational system (escuela infantil).

Once ***A*** is enrolled at the centre, priorities are defined for the child and his/her family. As concerns ***A***, he/she needs to continue physiotherapy at the hospital three times a week, but he/she also needs to begin a more general stimulation programme. The team psychologist will follow the child's developmental progress. An application will be lodged with the social services responsible for persons with disabilities (Imserso) to take charge of medical care and stimulation. At this point, the hospital no longer follows the child.

Given the family conditions, a specialised educator reporting to the local social services works with the family: moving house is desirable, the family dynamics are not always the best, the parents must be helped in taking charge of the child. Meetings are held with professionals, organised by the early intervention team. Exchange and support work is done with professionals from the educational centre in which ***A*** is

enrolled at the end of his first year of life. This concerns stimulation activities as well as the necessary environmental adaptations and work at home. A specialised teacher goes to the school twice a week to work with ***A*** and once every two months, co-ordination work is carried out with the teaching team.

In **Sweden**, once the hospital has informed the county centre in charge of rehabilitation for children, someone from the centre will get in contact with the family for the first visit. Various professionals work there: pre-primary teachers, psychologists, physio-therapists and doctors. ***A*** will need various technical aids which will be provided by the hospital or the centre. The centre will handle the continuous follow up of the family which will be involved in any decision or measure concerning the child. The family is given guidance in establishing an individual programme for the child. Given the difficulties and the work to be done at home, a family aid is suggested. An assistant works at the home full-time.

Other, slightly different channels are possible in other countries. Parents are informed and supported in **Greece** within the.framework of medical structures. If the members of the medical-educational team feel it is necessary, they will ask other specialists to intervene. Special schools contribute by informing parents of the measures to be taken for rehabilitation.

In the **Netherlands**, when the child is under the responsibility of the hospital, early intervention measures particularly concern support to the family to help it accept the problem. Once the child is home, various functional treatments will begin (physiotherapy, speech therapy etc) and a social worker employed by the hospital or the rehabilitation centre follows the family. If he/she considers that the family can cope with the problems without professional support, the parents can regularly go to the family guidance services, open to all parents.

In **Portugal**, the hospital directs ***A*** and his/her family to a centre specialised in cerebral palsy. The centre's multi-disciplinary team - social worker, therapist and psychologist - follows the child and his/her family. This same team then gets in contact with the pre-primary teacher who will help the child develop communication skills. This support will continue for two years, at which time ***A*** will be directed to a child care centre whose staff has been given information, awareness counselling and in so far as possible are prepared.

In the **United Kingdom (England and Wales)**, follow up is provided by the various services reporting to the hospital. A social worker will go to ***A***'s home once the child has returned home to try to help the family adjust to the new situation. This professional will put the family in contact with a volunteer organisation to meet with other parents who are in similar conditions. The health visitor will also visit ***A***'s home regularly to follow the child's progress and to give guidance on health care. A hospital psychologist will be asked to assess ***A***'s general intellectual development.

Example B: A child of two with Down's syndrome, from a low social-economic group family, living in a rural environment

Different types of aids and measures provided for the child and his/her family

B's parents take the same steps as those undertaken by ***A***'s parents in the previous case. They are entitled to the same benefits concerning both financial support, under the same conditions. However, everything will be adapted in terms of ***B***'s needs.

Differences are evident - in relation to technical aids, for example which are not always necessary, or may be of a different kind. In addition, support for transportation is added, given the child's age and the family's living conditions. Other complementary measures may also be added to improve or compensate for the social and economic conditions of the family.

B's parents are informed of the benefits to which they are entitled and the possible additional benefits available in some countries.

In the **French Community** of **Belgium**, for example, the public centre for social aid ("Centre Public d'Aide Sociale", CPAS) can make a financial contribution, to help families with problems in meeting daily expenses. The child can obtain a 50% reduction on the price of public transport and there is a possibility to obtain a reduction on the price of public transport for accompanying persons. A removal and fitting out allowance or a new house can be granted if current housing is recognised as unhealthy or inappropriate for the disability.

In **France**, if ***B*** is going to join a nursery school, his/her case history records are passed on to the Special Education Committee for the Department and a special educational allowance is assigned if specific expenses are foreseen. These can be expenses associated with individual or collective transport from the home to school (and vice versa).

In **Germany**, additional financial aid can be granted via health care insurance.

(More information regarding this example situation in Germany, is available in the case study given in appendix 2).

In the **Netherlands**, parents can obtain financial support which covers the care needed, support for the family or the aid required to make the necessary adaptations in the home.

In **Portugal**, the Social Services help the family with transport costs for travel to the specialised centre supporting the child or to attend medical check-ups.

In **Spain**, once the child is recognised by the social services (Imserso), they bare transport costs and the cost of a private early intervention centre taking care of the child.

In **Sweden**, parents have the right to a complementary allowance determined in view of the disability. The family income is not taken into consideration for this allowance. The child will be entitled to transport by taxi to get to nursery school and back home.
(More information regarding this example situation in Sweden, is available in the case study given in appendix 2).

Organisation of early intervention

B's parents may encounter more problems in gaining access to services providing early intervention, given their home location and environment. This can range from minor problems in certain countries which can usually be overcome, to serious difficulties in other cases.

Among the problems mentioned are first of all increasingly difficult access to services which are less evident in a rural area. Transport must be provided to avoid limiting access to treatment and to the needed aids. Sometimes associations will provide an information service and support in rural areas.

Another difficulty to be considered concerns a greater chance of the family's lack of information regarding the disability, its scope and the measures to be taken.

At times there are also problems with regard to communication with families like ***B***'s. Messages are not understood in the same way and one must ascertain that they have been understood and followed.

In most cases, the child has been followed since birth, but possibly, in an isolated area for families whose social-cultural and economic level is very low, no stimulation has been given before he/she begins at the pre-primary school.

The various services made available to ***B*** and his/her family are organised in a way similar to that presented for the previous case, but take account of the child's different needs and family situation. A diagnosis is made at birth in the hospital, a stimulation treatment begins immediately afterwards. Support from other services can be added in some countries.

In **Austria**, immediately after birth at the hospital, a neuro-peadiatrician refers the parents to early intervention services. Problems may arise if the birth took place at home, which is very rare. There are local early intervention networks and peripatetic services for the most isolated zones.

In **Belgium (French Community)**, the maternity-ward staff directs the family to early intervention services. Travel problems may arise requiring more frequent aid. Other services must be involved: the CPAS, the "Service d'Aide à la Jeunesse" (SAJ-Aid to Youth service) which offers educational support, the APEP: "Aide et Prévention Enfants-Parents" (children-parents aid and prevention). This service intervenes and supports families in difficulty. The Social Assistance Ministry ("Ministère de la Prévoyance Sociale") can also intervene with non-repetitive support for the family.

In **Finland**, there are 14 districts for specific care. They provide care for persons with developmental disabilities. Various professionals work there: doctors, psychologists, social workers etc. They are in position to offer guidance, advice and rehabilitation. They can also organise courses. These same services can be provided by the Finnish Association for the Mentally Disabled, which is now establishing an information project in collaboration with the authorities for health and social affairs. This association has drafted material on early intervention, education and information intended for professionals in hospitals and health centres to help them pro-

vide support to families.

In **France**, the CAMPS (early medical social action centre) takes charge of the child from the very start. Subsequently, there are various possibilities: if the child is accepted in a mainstream nursery school, the pre-primary district committee takes responsibility in collaboration with a medical-therapeutic service (for example the CAMPS). The latter is the only partly responsible for the child if he/she remains in the home.

In **Germany**, information is given at the hospital after ***B***'s birth, referring to the different possibilities available within the early intervention services. There exist in the Länder a differentiated system of early intervention services. They are mostly organised by welfare associations, like Caritas or Lebenshilfe, or by the church (Diakonie).

In the **Netherlands**, ***B***'s case is taken on by the Social-Educational Service (SPD) which operates as an independent organisation, funded according to the general law on special illness costs (AWBZ). It takes charge of persons with mental disabilities and their families. Its role is to inform, advise, guide and support them their whole lives long. There are about 30 of these services in the entire country. Depending on the needs of the child and his/her family, other social or medical services may join in support efforts.

In **Portugal**, a support team involving the Ministry of Education will take on ***B***'s case. The support team can also include the Ministry of Health and Social Affairs. If it appears necessary, the local authorities will also be included. Close collaboration between the various authorities is important given the needs of the child and the family.

In **Spain**, ***B*** is first followed in a private, subsidised early intervention centre and afterwards, the family contacts a rural psycho-educational guidance team which gets in contact with the local school for very young children ("escuela infantil"). The early intervention centre for the area ge- in touch with the other services to co-ordinate the measures.

In **Sweden**, given the age of the child, the specialised pre-primary teacher working

in the rehabilitation team has an important role with the parents and the pre-primary centre staff. The Swedish Agency for Special Needs Education (SIH) also takes part in the work providing educational support.

In the **United Kingdom (England and Wales)**, ***B***'s family got in touch with the local Portage service which works with an Early Years team. As the child is integrated in a pre-primary class in a mainstream school, the local education authorities contribute to the educational support that the child will need in co-operation with the Early Years team.

Support to the child and the family

The various support strategies which are to be taken with regard to ***B*** and his/her family, concern all types of care addressed to persons who have a disability, or malfunction in their intellectual capacities and are needed to meet their special needs. This may involve regular medical check-ups to detect and treat any difficulty associated with the disability on a functional level, stimulation work to help them become more independent in carrying out daily life activities, developing capacities and actively participating in school activities later on. This also concerns guidance and support for the family at practical level: help in the house, changes and adaptations to be made; on a personal level: helping parents understand and accept the problem and its consequences; and for the child: active participation in the stimulation programme provided.

All these elements are provided, in a slightly different way, by services which take responsibility for ***B***'s case in the various countries. A few differences appear from one country to the next concerning the place the family lives. However, there is no doubt that the most marked difference lies in whether the educational system does or does not take part in early intervention, as part of the process of providing support to the child.

In a number of countries, educational services are directly involved in the early intervention.

In **Italy**, if there is a local pre-primary school, the child will be integrated into it. Educators will be responsible for his/her integration in collaboration with the

parents. Meetings will be organised with the school staff, the parents and the health services which provide the necessary care.

In **Norway**, the rehabilitation service will have the responsibility for ***B*** during his/her first year of life. It may make an assessment of the child's possibilities and limits during one week. The entire family is asked to participate with ***B***. This assessment is done at the same time for several children. In this way, the families can get in touch and exchange their experiences. Dialogue support groups for parents may also be set up.

The Psycho-Pedagogical Service intervenes to provide specialised educational support. ***B*** has preferential access to kindergarten in his/her area and support personnel are available to meet his/her needs.

In **Portugal**, the family is followed by the early intervention multi-disciplinary team. After evaluation the child is integrated in a pre-primary school and can benefit from therapeutic support in a specialised centre.

In **Spain**, ***B*** is followed by a private early intervention centre which drafted a programme of intervention from the age of two months, provided by the parents at home with joint working sessions every two weeks. This centre guides the parents to the local mainstream school for young children ("escuela infantil") when the child is one year old. Before the child enrols, a rural psycho-educational guidance team must issue an opinion. The parents choose another school, in town, despite the inconvenience this causes in terms of travel. The early intervention team in the area takes charge of ***B***'s case and co-ordinates the measures to be taken.

An information meeting is organised for parents whose children are to be integrated in a mainstream school, to explain the follow-up and the scope of the integration. It is agreed that ***B*** will continue to do stimulation work at the private centre whilst going to school. The flexible timetable means that he/she can go twice a week. The working programme done at home is known to both the area team and the school so that efforts can be combined. The class teacher and the specialised teacher of the area team work together on the programme to be carried out, which takes account of and reinforces the aspects worked on in the private centre. Initially, individual work is scheduled twice a week, but is dropped as a result of the

child's progress and is limited to supporting the teacher. Later a speech therapist does individual work once a week. Co-ordination meetings are organised on a regular basis.

In **Sweden**, ***B*** is placed in a mainstream pre-primary school. An assistant helps both at school and at home. Specialised pre-school teachers from the county rehabilitation centre provide support to both the family and the school staff. Together they draw up an individual work programme for ***B*** and set the dates for the assessment.

B has problems of low vision and needs additional light. The personnel at the opthalmological clinic adapt the child's environment at home and at school. The Swedish Agency for Special Needs Education offers guidance to the parents with regard to this problem.

The child is entitled to take swimming lessons organised by the rehabilitation centre, but he/she lives 300 Km from the centre and is not able to take part. Distance no doubt limits access to services. The specialised pre-primary teacher appointed to provide support, in fact visits the school only once every two months. Despite this, the parents do not want to move, because life in a small rural village also has social advantages for them and the child.

In the **United Kingdom (England and Wales)**, ***B*** and his/her family are followed by an Early Years team, in the local Portage service. This service worked with the child and the family almost from the time of birth. The work concerning five aspects of development: motor, language, cognitive, self-help and socialisation, is done in the home by the parents with the regular guidance and supervision of the team. The child also has speech therapy and physiotherapy with other professionals in the Early Years team. Meetings between various professionals regularly take place, all information concerning ***B***'s progress and the work to be done with him is recorded in detail.

B enters an integrated nursery class attached to a mainstream primary school. He/she has learning support assistance 50% of the time, support allocated via the statement of special needs. In the same class, another child is entitled to the same kind of learning support which means that in practice both have support 100% of the time. For this reason ***B***'s family decides to enrol the child in this school, rather

than a school nearer home.

Entrance to school is carefully prepared by the Portage service. The local authorities in charge of education contribute by providing training for the nursery staff which means they are well prepared to support the child and the family. At the time of enrolment, the teacher and parents fill in a very detailed entry profile "All about me", which is very helpful for the school staff.

B will be able to enter a mainstream primary school because the school has good resources for providing for children with severe learning difficulties. A specialised teacher is employed full time.

In other countries, the separation between the early intervention team and the educational structures are most marked, although preparation is provided for the transfer of care.

In **Austria**, early intervention services gradually decreases their role as the child's needs evolve. When the child is ready to go to school, their participation is finished; the task is taken up in the framework of special education.

In **Belgium (Flemish Community)**, the early intervention team establishes a working programme with the family which is assessed regularly. This programme includes activities with the parents: information about the disability, how to stimulate the child's development, psychological and administrative support, participation in discussion groups (six times per year), contact with other parents, information on pre-primary school centres and preparation for admission into school.

Work with the child and the family is done initially every two to three weeks and later once a month. It is done at home, with the child's caretaker or in the pre-primary centre. It targets developing the child's overall development.

Preparatory meetings and visits are organised in mainstream and special schools, to prepare the child's entry in school. The parents take part. Contacts are made with other services such as the Psycho-medical-social services (PMS). If the child is integrated in a mainstream school, the team continues to follow him/her for a certain time. If the child enters a special school, the team's work ends and the spe-

cial school takes over.

In **Finland**, the district health care service establishes an individual programme which takes account of the assessment of the child's development. When the child enters school, specific treatment can be organised during and/or after school time if necessary.

In **France**, the situation is complex, because various options are possible. If ***B*** is integrated into a nursery school, the pre-elementary and elementary district ascertains that the requisite conditions are met in the host school and sees that an individual school integration project is set up. This project sets the conditions for attending school, organises the support of a medical-therapeutic service and the co-ordination between the various parties involved.

If ***B*** remains at home, he/she is followed by the Early Medical-Social Action Centre (CAMPS), which establishes and monitors the therapy, rehabilitation and educational measures needed by the child. The child can also enter a structure created by parents associations for children with Down's syndrome which organises activities promoting the child's development.

When the child is three years old he/she can be enrolled in a "Institut Médico Educatif" (Medical-Educational Institution) if he/she cannot be integrated in a mainstream nursery school.

In **Germany**, the early intervention team takes charge of providing support to the child and the family. With regard to the child, it includes a physiotherapy programme in a weekly session at the centre and a rehabilitation treatment at home with the mother once a week, given by a special teacher. The treatment targets the child's social, emotional and intellectual development.

Support to parents is provided by a psychologist and a special teacher. It is given in response to needs expressed by the family. Co-operation between professionals is very close; weekly meetings are scheduled. Every six to eight months, the child's programme is reviewed and adjusted if necessary.

In **Greece**, the Health Centres in rural zones inform and take charge of the family

and the child. These centres include various professionals: doctors, psychologists, social workers, educators, speech therapists. When the child enters school, a special teacher in charge of the special classes prepares a programme in co-operation with the family. If need be, the child can attend a school in the city which provides better learning conditions in special units.

In the **Netherlands**, the child will be taken in hand by the Educational Social Service (SPD) which will provide the necessary support given his/her needs. The support is particularly addressed to the parents rather than the child. ***B*** is followed by a professional, a case manager. In general this is a social worker with specialised training. This social worker can help the parents find a place for ***B*** in a pre-primary centre or find a host family for a few hours per day.

Parents are also aided in stimulating and educating the child. The purpose is to answer specific questions mentioned by the parents in a small number of sessions. This is the job of a specially trained social worker, who is not ***B***'s case manager, via a practical family educational guidance programme (Praktische pedagogische gezinsbegeleiding). After 5 or 6 observation sessions, the programme is established for 10 to 15 working sessions with the family.

If the parents have further questions on the child's development, a programme like the Portage or the Macquarie is set up. For more general questions, meeting are organised with other parents who have the same interests.

Example C: A four year old child with a severe hearing impairment, in a medium-low social economic group family, living in an industrial environment

Different types of aids and measures existing for the child and his/her family

C 's parents undertake the same steps as those taken in the previous cases. They are entitled to the same benefits concerning both financial support and aids, under similar conditions, but adapted to the child's needs. Family allowances are granted; the parents are entitled to the social advantages awarded to families with a disabled child.

Additional financial aids are granted, moreover, particularly for technical aids like audiophones, and other treatment needed given the child's hearing impairment: check-ups and follow up in audio-logical clinics or in ear, nose and throat wards in hospitals.

The differences from one country to another concern the scope and financial coverage of the measures set up for the child.

In **Belgium (French Community)**, financial aid is provided for hearing aids, via non-recurrent grants from the Walloon Agency for integration of the disabled. Certain companies may also contribute to the costs incurred for the child. The **Flemish** Fund also provides financial support for the hearing aids.

This is also the case in **Finland**, where all hearing or other aids are provided by hospital services at the expense of the local authorities.

In **France**, the Departmental Commission for Special Education can grant financial aid if the child is integrated in a nursery school, for courses given by associations or private organisations.

That is also the case in **Italy** and in **Luxembourg**, where the local health authorities cover costs associated with fitting the child with a hearing aid.

In **Norway**, any additional medical examination is free of charge. Transport costs to the hospital are covered. ***C*** can benefit from support at home, plus four hours home care assistance per week and one week-end per month.

The child's parents attend 40 hours of sign language courses to which they are entitled by law for the first 16 years of the child's life. All costs associated with this are covered: travel, handling for parents and brothers and sisters not yet of school age. Courses can also be organised by the Norwegian Association for disabled Persons, in collaboration with the National Association for the Deaf, for other family members and friends.

C is entitled to standard allowances covering the cost of batteries for the audiophone, special toys and books that the child may need. The family can also benefit from additional allowances in an effort to make up for the extra work needed to care for the child given his/her deficient language skills. In the case of ***C***, they are entitled to type 1 allowances, in addition to the standard allowances. *(More information regarding this example situation in Norway, is available in the case study given in appendix 2).*

In **Portugal**, the child is led to a hospital, free of charge, for an infant deafness, ear, nose and throat consultation. A multi-disciplinary team in this service directs the child to an educational unit, with expertise in the area.

In **Sweden**, parents also benefit from additional allowances granted by the social services, covering 50% of extraordinary expenses entailed in caring for the child. Any technical aid is free of charge. This also holds for the adaptations to be made at the pre-primary centre attended by the child. In the case of ***C*** , the Centre of education and training of children with hearing impairments attached to the county, installs a hearing loop at the school. The cost of this technical aid is borne by the county and rented to the school. The rental means that the school bears the cost of installing, maintaining and removing the equipment. If other measures or adaptations are necessary or are taken, such as acoustic tiles, the cost is borne by the local authorities.

Organisation of early intervention

As a starting point, the degree of the child's hearing loss must be considered. This is measured in the various countries in the audiological wards in hospitals. Co-operation of the child and the family is very important if this is to be done well.

The services, centres or organisations in charge of early intervention then take part in the support to the child and his/her family. The general organisation of these services is the same as that described for the previous cases, save a few variants. The following situations summarise the various possibilities open to ***C*** 's parents in the different countries.

In **Belgium**, ***C*** can attend a special, type 7 nursery school as from two and a half years old. (This provides teaching adapted to the educational needs of pupils suffering from hearing impairments). This is the option chosen most frequently. In this case, the special school will take on the work to be done with the child and the family. The child can also attend a mainstream school and is entitled to specific support in that educational framework.

In **Finland**, there are five university hospitals and sixteen general hospitals which have an audiological clinic. In general children are given their first orientation by the university hospitals and the Central Hospital of Finland, which takes the main responsibility for treatment and care for children with hearing impairments in the first years of their lives. The child will be followed in mainstream or specific pre-primary centres, the hospital or the Finnish Association for persons with hearing impairments, which offers its services.

In **France**, a family accompaniment and early education service monitors the child until the age of three. Afterwards, the Departmental Commission for Special Education and the family choose between integration in a nursery school or enrolling the child in the nursery school section of a medical educational institution for deaf or hearing impaired children.

In **Germany** and in **Austria**, the early intervention centre follows the child and the family. Given the impairment, the ear, nose and throat services of the hospital, as well as a paediatrician or a neuro-peadiatrician regularly intervenes. Co-operation

with the pre-primary centre is very close.

In **Greece**, support can be provided in the framework of the Child Guidance Centres, or by mainstream or special nursery schools.

In **Italy**, the child will be under the responsibility of the local nursery school with the support of the local social-health services.

In the **Netherlands**, *C* and his/her family will be followed by one of seven organisations providing guidance to parents of children with hearing impairments in the country. These organisations work with the child from birth to the age of five.

In **Norway**, the county has an education officer responsible for the deaf. This person will follow the child in collaboration with the Psycho-Pedagogical service which creates and co-ordinates a group to work with the child. Professionals from various services are associated with this group: parents, the county official, a pre-primary teacher from the Psycho-Pedagogical Service, a teacher and an educator from the pre-primary centre, a social worker for the social services.

In **Portugal**, the child is followed by the ear, nose and throat service in the hospital. He/she is directed to a nursery school, where an educational team supports the child.

In **Spain**, the early intervention team for the area co-ordinates the measures. *C* applies for enrolment in a school for the integration of deaf and hearing impaired children. The child has rehabilitation treatment in a private subsidised centre specialised in language problems and deficiencies. *(More information regarding this example situation in Spain, is available in the case study given in appendix 2).*

In **Sweden**, once the paediatrician has detected hearing problems, the child is guided to a university hospital for audiological examinations. From there, he/she is taken in charge by the County Centre for the education and training of children with hearing impairments. Work is done in close collaboration with the child care centre.

In the **United Kingdom (England and Wales)**, ***C*** is in the reception class of the mainstream primary school. The school is responsible for following the child and for the educational aids that the child needs. An audiologist and the local official in charge of the service for persons with impaired hearing are in contact with the school.

Support to the child and the family

In a large number of countries, ***C*** has already entered the educational system. In a few countries, early intervention teams have already finished their stimulation work with the child and have prepared the child for the transition to mainstream education. This is particularly the case if ***C*** enrols in a special nursery school for deaf and hearing impaired children. In the case of integration, the teams can still offer occasional aid, at least for a certain amount of time. In other countries, they work closely with the pre-school institutions and continue to offer support to the child, the family and the school staff.

The age at which the child's hearing loss is assessed is quite variable. This is entirely possible if the child does not present other problems and if the loss does not exceed 50 -60 dB. The delay in the development of language skills can be manifest as from two years old if the family and the family doctor or health centre doing periodic check-ups are very attentive, and it is possible that the child has no treatment before the age of three. The situation is different for children having a history in the family: if one of the parents or a brother or sister has also a hearing impairment.

In **Austria**, the ear, nose and throat specialist makes the diagnosis and sees the child regularly. If the child enrols in a special school, no measures are undertaken by the early intervention services.

In **Belgium (French Community)**, ***C*** is followed by an early intervention centre which gets in contact with the school which may subsequently enrol the child. This choice is made in view of the opinion of the team, the parents and the child's possibilities. If the child is integrated in a mainstream school, he/she will have specialised support 4 periods per week, in general provided by professionals from a special school. He/she may also receive paramedical support in a specialised insti-

tution or at home, outside school hours.

In the **Flemish community**, this support in a rehabilitation centre or at home, takes place once a week. It also includes information and discussion groups. In each province, there is a support centre for children with hearing impairments and their families.

In **Finland**, ***C*** and his/her family are taken in hand by an audiological clinic where various professionals work. Support to the child focuses on developing language skills, rehabilitation of hearing, social and personal development. The same work can be done by the Finnish federation for the deaf and hard of hearing. Speech therapy and communication is done once a week.

Various types of support are planned for children when they enter primary school. The family is advised about the courses given at the hospital by the Association. In the hospital framework, one information day is organised for the parents per year, and five for the entire family. Information provided concerns technical aids and various means of communication. Sign language courses can be organised if the child needs them.

In **France**, as from three years old, the Department Special Education Committee consults the family to see what means of communication is chosen: a single language (oral French) or bilingual (oral French and sign language). The choice determines the support to be put in place or the institution suggested to the family. ***C*** can be integrated in a mainstream nursery school or in the nursery section of a medical-educational institution for the deaf and hearing impaired.

In the first case, an integration project is drafted stipulating the specific conditions of the child's schooling and the aids to be provided by specialised services like the Educational Family Support Services and School Integration or others. These services can provide the child with assistance (part time) of interpreters or cued speech guides.

In **Germany**, a clear example is provided where ***C*** has completed several private sessions with a speech therapist; this stopped with the child's refusal to cooperate. Just before his/her fourth birthday, the child is taken in hand by the local

early intervention service which completes a report on his/her capacity and hearing potential, in collaboration with an ear, nose and throat service and a neuro-paediatrician. The hearing loss is estimated at 60 dB. The parents' attitude is rather ambivalent: the mother also presents a hearing loss and has an unpleasant memory of her hearing aid; the father does not accept the situation well. Both are looking for treatment to "cure" the child. The working programme must take account of all these factors.

C attends an individual rehabilitation session once a week at the early intervention centre with a specialised teacher who tries to improve his/her capacity to communicate and exchange with others. In some Länder, this could be done in the school for hearing impaired children. He/she also receives speech therapy once a week. The specialised teacher occasionally goes to the child's pre-primary school to exchange information and guidance with the personnel caring for the child.

Meetings with the family are scheduled once a month to talk about the hearing aids the child needs, to facilitate communication and co-ordination between the parents, the educational centre and the medical services and to help the parents accept the child's impairment.

In **Greece**, *C* and his/her family are supported by a specialised centre. Support and guidance are provided in the centre or the home. Professionals can intervene with other members of the family if this proves necessary. The child can take part in mainstream primary classes which have special units for children with hearing impairments.

In **Italy**, if the child enrols in a public nursery school, he/she will be aided by a specialised teacher for 16 to 20 hours a week. This is the case for the duration of nursery school. The teacher, support teacher and family establish an individual working programme for the child.

If *C* is in a private nursery school and his/her impairment has not been officially recognised, he/she is not entitled to a support teacher paid by the local educational authorities. In general, in these cases, the private school hires specialised teachers on behalf of the child.

In **Luxembourg**, ***C*** and the family will be followed at home by the early intervention services. At four years, ***C*** will start compulsory education and the child will be supported by the National Speech Therapy centre. The child will learn the German language. After a few years, ***C*** could attend a mainstream school, providing the necessary support.

In the **Netherlands**, ***C*** is followed by one of the guidance services for families of deaf and hearing impaired children. A programme is established which particularly targets communication between the child and his/her parents which could prevent development and behaviour problems in the future. The parents must learn to communicate with the child; they are given courses and must practice at home to learn to "talk" to the child (for example, they may learn sign language). At the same time, they are informed about the impairment and its consequences and receive support to better accept the situation. If the problems concern daily activities, temporary teaching aid is provided, usually at home. In all, this requires on average about 115 hours of work per year together.

At the age of 4, ***C*** enters a special school for children with hearing impairments. The educational structures provide support to the family when necessary. Parents are encouraged to continue their training in sign language and to take part in parental support groups.

In **Norway**, ***C's*** problem is detected and confirmed at the age of 3 due to the insistence of the parents with the local health centre which did not perceive there was anything to worry about. The family, conversely, is increasingly concerned about the child's poor language skills. After confirmation by the ear, nose and throat specialist at the audiological centre, he/she is given a hearing aid. The family meets the county official responsible for education of children with hearing impairments, who puts them in touch with the Psycho-Pedagogical service. This service aids the child, the family and the school on any educational questions. At times this service is not competent for hearing impairments, since it is fairly rare, particularly in scarcely populated areas or in small towns.

Due to the child's hearing loss and its late detection, he/she will need special education. He/she will learn sign language. A specialised teacher follows the child individually six hours a week, or with other children in the kindergarten where the

child is enrolled and he/she is aided by an educator half-time. The educator works with ***C*** in a group of children.

C is the only child with a hearing impairment in the school. At local level, there are two other children who also have hearing impairments, although they are less serious. To allow the child to meet other children under similar conditions, a visit is planned for him/her and his/her parents at the pre-primary centre for children with hearing impairments which is run by the county hospital. For two weeks in the spring and two weeks in the fall, they will meet other children and other parents and take sign language courses. The staff visits the centre where ***C*** is enrolled and may meet the staff of the psycho-pedagogical service. In a few municipalities, this same process is carried out with a resource centre for the deaf and hard of hearing.

In **Portugal**, ***C*** gets a hearing aid very early, and is followed by an ear, nose and throat specialist. He/she is integrated part-time in a nursery school and followed by a special centre for the deaf and hard of hearing. Regular meetings are held among all professionals taking care of the child in order to set up an individual educational programme, monitor and assess the child's progress and exchange ideas by drafting a joint report. Together they prepare the entry in primary school.

Collaboration and participation of the family is very positive, particularly the mother. This no doubt promotes the child's progress.

In **Spain**, ***C*** presents a bilateral hearing loss of 80 dB. His/her brother also shows a hearing impairment. The parents are very much aware and well informed about the impairment, which means that it is detected quickly and early intervention is possible. Audiological aids are allocatted and adjusted, in order to work as early as possible with the residual hearing capacities with support from lip reading.

From the age of three months, the child attends a private, subsidised centre specialised in language problems and working with alternative systems of communication. He/she does individual speech therapy for three sessions a week and stimulation sessions in a group twice a week.

The early intervention service for the area enrols the child in the local nursery

school (escuela infantil) and provides co-ordination of the various services involved. The communication system used by the child both in the centre and at home, is Cued Speech. The support work is done mostly by teachers in the educational centre in collaboration with the private centre which periodically gives information on changes to be made. The child is later enrolled in an integrated primary school for deaf and hearing impaired children.

In **Sweden**, the loss was detected at a paediatric check-up at the age of four. The university hospital estimates the loss at 40-50 dB. The child gets a hearing aid immediately and is guided to the centre for the education of children with hearing impairments where they can be supported by a specialised teacher, a psychologist, a sign language teacher and a social worker.

The child goes to a pre-primary school. The team of the centre gets in touch with the staff of the school, in agreement with the child's parents, to inform staff members of the child's problems in order to help them in their work. Co-operation with the pre-primary centre consists above all of an effort to inform the staff about the child's needs, working conditions for the child and the class: speak to him/her straight in the face, work preferably in small groups, maintain good acoustical conditions. Material support is provided to the school to improve the working conditions.

Once a month, the specialised teacher goes to the school and works with the staff. A local pre-primary school for children with deficient hearing can enrol ***C***, but the parents are not interested in this possibility. Contact is made with another family in a similar situation. The centre organises meetings with the parents at least once a year, so they can meet and talk to other parents. A meeting is also organised with other family members and friends that the family wanted to invite, in order to inform them.

In the **United Kingdom (England and Wales)**, ***C*** gets a diagnosis very early, since his/her brother also shows a hearing impairment. The child is enrolled in the reception class of a primary school, which is quite a distance from the family home, but which provides good support. The school has a section for pupils having hearing problems. The child benefits from the support of a specialised teacher for hearing impaired children who works full time at the school. The teacher teaches sign

language; a fair number of teachers and pupils also know at least a few signs. The classes have good acoustics, the teachers are used to audiphones and to facilitating lip reading. None of these conditions is met in the local school. The school is sufficiently well informed and prepared - it will not need any outside support.

C gets individual lessons or courses with other children like him/herself, outside of the mainstream class in order to reinforce his/her achievements, the new concepts and to develop sign language. The school also has a learning support assistant, specialised in developing language, without financial support of the local educational authorities. This assistant is scheduled for other students, without hearing impairments but who have language and communication problems. In fact, he is very helpful to *C* in implementing the treatment decided by the speech therapist that he meets on occasion.

CONCLUSIONS

Before concluding, two remarks are required in order to help to place this study in the overall context of early intervention and to prevent any errors in the interpretation of the information contained in it.

First and foremost, this document aims fundamentally to offer information in as complete a way as possible and give an overview of the situation concerning early intervention in seventeen European countries.

There has been no attempt to make an assessment of the situation in the various countries, nor to evaluate the quality of services. This might be done in the future in each country in view of well defined criteria and objectives.

Secondly, the examples presented in chapter 6 and the case studies in appendix 2 cannot claim to be representative of the actual situation in the various countries, although they do illustrate existing practice. For the most part they are "success stories" and the elements appearing in them can be considered as those likely to promote favourable results. This is also true for the elements which could be interpreted as problematic - or difficult - which will help reflection upon conditions favouring successful early intervention.

With these two preliminary comments in mind, the various aspects mentioned in previous work can be considered - *organisation of services*, *early intervention teams* and *work with families* - as well as identifying the common elements, changes, new elements and trends which appear in this document.

Generally speaking, one can say that the results of previous work are still valid, without major changes being evident in the countries. Nevertheless, information has been completed, enabling a more subtle analysis. In this sense, there is no

doubt that the participation of a larger number of countries has enriched the information available.

Organisation of services

The common elements can be summarised as follows: in the various countries there exists a wide variety of services, which try to be as accessible as possible, are usually decentralised, which are organised by different authorities and which require good co-ordination.

This diversity which at the outset is an advantage for the child and his/her family, carries a risk of scattering of services and confusion for the parents. From this standpoint, co-ordination becomes common practice in some countries, to avoid wasting time and to rationalise the support to be provided and the tasks to be carried out.

Among the various services responsible for early intervention, those organised by the health and social affairs authorities are the most common. Education is more actively present than it was in the past. In a few countries, this is the case even for very young children, particularly in countries where the educational structures enrol children at a younger and younger age.

Early intervention teams

Two aspects should be delineated - functions and the tasks to be undertaken. In considering the first of these, common elements can be identified: diversity of professionals involved, different types of teams, a high level of professional experience and also organisation.

The types of team are not the same from one country to the next, although they present considerable similarities concerning their functions and with regard to the professionals involved. Indeed, the diversity of professionals needs clarification. These teams have a small, common core which in fact covers the four essential fields of early intervention: medical, psychological, educational and social fields - other professionals may be added as needs arise.

Another important element that is identified in a few countries has to do with the functioning within the team. Here, co-ordination is emphasised and the break down of tasks is done very systematically which, amongst other things, avoids multiple contacts with the family.

A new element is the constitution of early intervention teams organised by the educational authorities in a few countries.

As concerns the second aspect - the work to be undertaken - the common elements can be summarised as follows: the earlier the intervention the better; this is mentioned everywhere. This is accompanied by an overall assessment of the child's potential which will determine the support to be provided.

Other elements are pointed out concerning prevention, the care procedures for the child and the transition into the educational system.

The importance placed upon all forms of prevention is highlighted by many countries, which feel this it is not sufficiently emphasised. Intervention as early as possible, as a means to avoid more serious problems in the future is an issue raised by many countries.

Support offered to the child is the same with regard to content, but the delivery procedures change. This is apparent in two senses. On one hand there is a trend for the child to stay in his/her home environment as long as possible and to avoid institutionalisation. On the other hand, there is a growing trend to have the work done at home by the parents, particularly for infants, or at least with the involvement of the parents.

Finally, aspects associated with transition to education in school are highlighted far more clearly than in previous studies. Firstly, the importance of starting school for the child is underlined. This needs to be well prepared. Early intervention work takes this into account, informing and preparing both the parents and the school which is likely to enrol the child. From this, another element can be identified: once the child has started a pre-primary centre, the support work will be done with the child as is needed, but also with the teachers in the educational centre. The transfer and exchange of information has a fundamental role. Secondly, special

schools can play a role in supporting and providing information for the children and their families, without providing care directly.

Collaboration with families

It can be said that consideration for the needs and interests of the parents is always mentioned, as was the case in previous studies. Informing families continues to be a point that is very often emphasised.

A few elements must be added. Financial aids and measures targeting practical support are quite important and cover different fields. In all countries, additional allowances, tax reductions and technical aids are provided and ensured by public or equivalent services (like insurance companies for example).

Fairly marked differences appear with regards to other forms of support, such as support at home and access to "relief" families.

Although this document underlines all the achievements and the good work which is done, a few comments must be made on "critical" aspects, which will allow reflection upon what remains to be done in the future. These points were all raised by the professionals who contributed to this document.

The first of these is concerned with the practical difficulties associated with the co-ordination of services and professionals. Although this seems evident, at times this co-ordination is possible as a result of individual efforts only, rather than as an organisational measure or strategy.

There are also differences in relation to the work of the teams. For example, although the resources which are designated in the various localities may be the same, there can be differences which are often associated with the skills of the professionals working there or with the fact that these resources are not always available. The consequence will be differences in results. The services are not as complete and accessible in small towns as in large cities, which may limit care and measures despite the efforts made.

Information to the parents remains a delicate issue. Much has been done, but very

often there are still shortcomings which could have been avoided. For example in the case of seriously disabled infants, or in life-endangering situations, priority is given to the child's survival without informing and warning the parents of the consequences, which will have double impact: forcing them to face the possibility of death and coping with a disability.

The parents' contribution needs to be underlined, particularly that of parental support groups when services are not available. Despite widespread recognition of this contribution, in few countries are they truly responsible for decisions and for the work to be done with the child.

The socio-economic level of the family should not be a limiting factor in theory: this is clear in the provisions and legislation. However, in practice, this may not be the case. Problems can arise in rural zones, more so if they are isolated. The most disadvantaged families also have more limited choices: access to and comprehension of the information may be restricted or, more limited.

Finally, problems of detection are not handled in the same way. Early detection is more common in families with a high socio-economic background, unless the family is already being monitored because of risk factors.

All the elements listed allow us to remain optimistic with regard to progress that has been made, as well as being realistic and modest concerning the current situation and vigilant about what remains to be done.

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Appendix 1

Helios questionnaire

1. What does the law say about support to families with children with disabilities from age zero to school?

a. Is it laid down by law in your country that families with children with disabilities are entitled to support?
b. What are the legal provisions on this issue?
c. From which age of the child can the child and the parents get support?
d. Is the support given by the public authorities or private organisations?
e. Which bodies finance early intervention? (State, local-regional authorities, private organisations)
f. Do parents receive financial support/compensation? In what form, and/or under which circumstances?

2. The organisation of early intervention. How is the provision of early intervention organized in your country?

a. Who or which institution is responsible for providing the early intervention?
b. Is there a specialised team responsible for giving the support specifically for these children?
c. The professional background of the team members (psychologists...)
d. Can the team attach persons with other specialist backgrounds?
e. Is provision of early intervention in your country organized at national or decentralized level (subnational, local, regional authority)?

3. Support for the child and the parents

a. Who provides support/service for the parents? The State, the local authorities, private organisations or other bodies?
b. How is the support for the child provided? Out-patient clinic, at home, with other children with disabilities?
c. How often does the child get training/therapy? (daily, weekly...)

d. Do the parents have access to a relief family for the child? If yes, for how long?
e. What kind of assistance is offered to the parents? (Social worker, psychologist, others)
f. Do you have organizations of parents with children with disabilities? If so, what is their role?
g. Do the parents have the possibility of psychological assistance, either in groups or individually?
h. Are parents offered training? 1. Special courses 2. General courses of longer duration
i. Are such courses open also to grandparents?

4. Integration of children with disabilities in kindergarten

a. Are all children with disabilities being taught (trained/educated)?
b. Do the families get the chance to choose the institution (kindergarten) they find the best? Are there waiting lists?
c. What is common in your country. Integration or special institutions?
d. Is the expert team's knowledge about the child passed on to the kindergraten and school?

5. Where may the professionals seek knowledge, information on special disabilities?

a. Is there special further training for professionals?
b. Who pays for the training of the professionals?

6. The tendency in your country concerning early support, early intervention

a. What is the general tendency in your country concerning early support?

Appendix 2

Case study A: A new born child presenting a brain injury

Family situation
A is living in Flanders (Belgium), in the country, 20 km distant of a city, in a working class family.

Child situation
There was a problem of deficiency of oxygen after birth. The mother was concerned about the development of the child because of little motor activities at the age of 10 months: the child was not able to roll over, sit or grab toys.

The child was referred to the early intervention centre after a consultation in a centre for developmental disabilities ("Centrum voor ontwikkelingsstoornissen", CVO). The mother regularly phoned the centre.

Organisation of early intervention
One week after the consultation in the CVO, there was a first house visit by the remedial educationalist ("orthopédagogue") and a physiotherapist. The first meeting was about the problems at birth and the mother feelings. She mentioned the problems and differences of her ideas and those of her husband in accepting the child's situation. It was also about the things the baby could do and the mother explained how the baby had learned to do things.

Information was given to the mother concerning the first observations of the child and results. This was very important for her as she got confirmation of her impressions. On the other hand, the possibilities for further development and stimulation were put forward.

Finally, the activities of the early intervention centre were explained and a weekly visit schedule was decided at home and at the place of the person who was babysitting the child.

Support

As result of the visit the remedial educationalist and the physiotherapist planned the support to be given. It consisted of the follow up of motor development and a search for technical means to make the child's functioning more easy. Support is also given to the daily interaction and handling with the child.

The remedial educationalist looks for adapted possibilities for playing and follows up intellectual development. As far as possible the mother is involved. Time and attention will be given to the complex family situation: other children and the more distant position of the husband.

After some months a private physiotherapist gets involved mainly to increase the frequency of the therapy sessions (Bobath therapy), without laying too much stress on the mother. Therapy is given three times a week at home or at the baby-sitter's place.

Early intervention support goes on by means of co-ordinating all interventions, to follow up the child development and to support the mother through the house visits.

The main objective of the support process is to support the family in a way so that they can manage to educate and to live together with the person with a disability in their family. Therapy or treatment as such is never the main objective. At the start there is a support programme signed by the two parties. The number of interventions will depend on the needs and wishes of the family.

Follow up

At the age of 18 months a speech therapist is asked to give advice on the problems related to eating and language communication, due to the fact that the child has a very communicative attitude.

At the age of 2 years the child is a nice pre-schooler with an obvious drive to explore himself and the environment. The functional motor abilities still exist: he can't sit by himself, he doesn't crawl but he is able to turn over. He can't eat alone. He has some technical aids to sit and to stand up. His communication abilities are also limited, on a non-verbal way he indicates what he wants.

At this time the question is raised wether ***A*** should to go to a specialised day care centre were different therapies are offered in combination with day care. Visits to schools are planned and discussed and the way is opened to go to a special school for children with a physical disability.

When ***A*** goes to school the support of the early intervention centre stops. Contacts are maintained by the phone or a house visit from time to time. In this way contacts will decrease although the mother knows she can contact the centre whenever she feels the need to do so.

Case study B (1): a two year old child with Down's syndrome

Family situation

B lives in Bavaria (Germany). The father is a construction worker. There are two children in the family: ***B*** and an older child who is suffering from a rare bone disease, which needs frequent hospitalisation. The mother is under a severe emotional strain because of their poor health and she is mainly responsible for the daily care and therapy of the children.

Child situation

B is a two year old child with Down syndrome. Following a heart operation that saved the child's life at the age of six months, the doctors at the hospital referred ***B*** to the early intervention centre in the town the family lives in. The child's development in the area of primary motor skills and fine motor skills is markedly delayed. Speech and articulation are severely impeded.

Organisation of early intervention

B has been receiving physiotherapy since the fifth month after birth and remedial therapy by special education personnel during the first year of life (this still continues).

Early intervention therapy is financed partly by the health insurance and partly by the local authorities where the family lives, as laid down in the German Federal Social Security Act ("Bundessozialhilfegesetz"). Furthermore, a small percentage of the costs of parental counselling are borne by the institution responsible for the early intervention centre, the "Bundesvereinigung Lebenshilfe", a nation-wide

association that provides facilities for people in need. A social worker will give a legal advice on financial assistance available through the nursing insurance.

Support

B's treatment covers mainly two areas: physiotherapy and special education. The child has received physiotherapy once a week (40 minutes) for the last one and a half years. For the first six months, ***B*** got treatment at home, after which the child went to the early intervention centre in the family home town, as the facilities and equipment there meant that the course of therapy could be better geared to stimulation of individual capacities.

Along with the physiotherapy, ***B*** receives remedial treatment from a special educational personl once a week (40 minutes). This takes place at home in the presence of the mother, and is intended to stimulate the social, emotional and intellectual skills of the child. With the help of games and toys this treatment promotes all areas of the development: primary and fine motor skills, speech, musical skills, painting and drawing.

At the beginning of the early intervention, the family was visited twice by a psychologist and a special education person, in order to determine therapeutic treatment that would help the family as a whole. Both parents were present.

B is still under the care of the same teacher today. If the need arises ***B's*** mother has an opportunity to talk to the therapists after the child sessions. Topics such as coping with the child's disability, developmental prognosis and the child's prospects for the future are covered on these occasions.

An inter-disciplinary co-operation is established among specialists: close co-operation between the physiotherapist and the remedial teacher; exchange of information during weekly team sessions in the early intervention centre, and six monthly visits by the physiotherapist during remedial sessions by the special teacher and vice versa. Every six to eight mont'hs, ***B's*** therapy programme is reviewed by the team of experts composed of ten specialists from a variety of fields, any necessary changes are discussed.

Follow-up
B is a well balanced, happy child, taking interest in the toys and games used in therapy and is co-operative during sessions, trying things alone, demonstrating a marked perseverance. The child can already produce sounds.

The mother can now cope better with the problems in her child's development, and mother-child interaction and communication has a positive influence on ***B's*** progress.

Case study B (2): a two year old child with Down's syndrome

Family situation
B lives in a little village in Sweden with only 100 inhabitants. The family have earlier lived in a big city, but they were not happy and now they are back in that little village where the child was born.

The father is a building worker and the mother is a cleaner. ***B*** is the youngest of three children.

Child situation
Immediately when ***B*** was born, you could see that something was different. The child has Down syndrome. The everyday life was changed. The child is now two years old and keen on funny things. ***B*** is very fond of the sisters and likes to play with them.

In the eye clinic, the doctors have found out that the child is shortsighted and needs glasses. ***B*** also has a minor heart condition that doen't cause too much trouble.

Organisation of early intervention
B attends a mainstream pre-school. Special pre-school teachers from the county council's child habilitation centre provide support for both parents and staff at pre-school. Together they set up an individual plan for the child and decide on a day for evaluation. The family has also access to a psychologist and a welfare officer from the habilitation centre.

Support
B has been given a place in a mainstream pre-school with an assistant who follows

the child both in the pre-school and at home. The child goes by taxi to and from the pre-school and it is free of charge.

Personnel from the low vision clinic have adjusted the environment at home and in the pre-school. The child needs some extra lighting and glasses, those will be free of charge. From the Swedish Agency for Special Needs Education the family gets advice and support concerning how to deal with ***B's*** shortsightness. The specially trained pre-school teacher gives advice about, for example, suitable toys.

The child has weak muscles and gets treatment from a physiotherapist to train his muscles. The child has also been offered the chance to participate in a swimming group at the rehabilitation centre.

The child and the family get, due to the disability, some extra support from both the State and the local authorities. From the State the parents get an allowance. It is 7500 Swedish kroner (868.5 ECUS) per month and it has nothing to do with the family income.

Children with disabilities have the right to and should get personal development and education equal to others in society. However, there are differences between the service you get if you are living in a town near to the county council's child habilitation centre, the low vision clinic and other facilities.

B and the family live 300 kilometres away from these facilities and therefore the child, for example, has no possibilities to participate in the swimming group. Also the special trained pre-school teacher visits the child only every two months.

This family are agreed that the advantages of living in a small village far outweigh the disadvantages. They enjoy the peace and friendly atmosphere.

Follow up

B will remain in the pre-school and will have the same assistant during the pre-school education, until six years of age. When it will be time to attend the compulsory school, it will be necessary to give information about the special arrangements the school will need to make.

At the age of six the child has developed many abilities and has no difficulties in walking and communicating, even if language is limited. Sign language and pictogrammes are both complement to the child's vocabulary.

Case study C (1): a four year old child with a severe hearing impairment.

Family situation
C lives in Norway in a middle level class family. ***C*** is the youngest of three children.

Child situation
In the last year, ***C's*** parents have been concerned by the fact that the child is not able to speak as well as their oldest daughter did at the same age. They had taken ***C*** to the local health centre until the child was two years old. ***C*** was reserved and withdrawn and not particularly co-operative. The health visitor could hardly hear ***C*** utter a word. The mother did not mention anything concerning the child who was not referred to any specialist.

When the child was about four years old, the mother accompanied ***C*** to the next examination. The child had only developed a few words and the mother was worried. She thought that ***C*** was too often "wrapped up in his own world". Sometimes she believed that the child heard things, on other occasions she could not be sure. The child was therefore referred to the Ear, Nose and Throat Department and the Hearing Centre.

Organisation of early intervention
In each municipality in Norway there is a municipal health service consisting of health centres having a particular responsability for attending to the development of small children. This service is free of charge and ensures a vaccination programme over the first two years of the child's life, a regular medical examination focusing on the child's growth, nutrition, psycho-social relations and linguistic and mental development. The quality of these services varies considerably between the municipalities and depending on whether the health visitor posts are filled and on each health visitors competence.

The health centre refers the child to a specialist if there should be any doubt about

their development. Travelling expenses to the hospital are covered and examination is free of charge.

A doctor and an audiologist produce for ***C*** the diagnosis of severe hearing impairment at the Hearing Centre. After two to three weeks another appointment was fixed for the allocation and adjustment of a hearing aid.

In agreement with the parents, the child was referred to the county education officer for the deaf. The officer provided information on the different measures that could be needed in order to attend to the child's needs. In each county there is an education officer for the deaf; this service is appointed by the State. The education officer told that they might contact the Pedagogical Psychological Service (PPS) in the child's municipal residence.

Each municipality is to provide a PP service that is supposed to assist parents, kindergarten and schools and it is responsible for organising a support programme for children with special needs. The municipal PP office has the overall responsibility for co-ordination of services on a municipal, county and national level. Many PP offices have, however, limited competence in the area because hearing impairment is a disability with a relatively low frequency, especially in places in Norway with a scattered population.

Support

C goes to a kindergarten. As the child has special needs, if there was not a place available, ***C*** would have had a preferential right on the occasion of the next admission.

To ensure the child's linguistic development and to make sure that the child is able to understand and to be understood, ***C*** should be taught sign language. A special teacher will assume the overall responsibility for the instruction in the kindergarten and someone will assist the child most of the day. ***C*** is allotted six hours a week with a special teacher and a pedagogical assistant on a half-time post. Generally the special teacher works alone with ***C***, sometimes he includes other children in order to expedite the child's linguistic development. The assistant works with ***C*** in the childrens group, explaining, communicating by the use of signs and preparing the development of communication and speech.

The parents' work load is considerable. They need to talk to their other children without being interrupted. It is difficult to find a baby-sitter with competence in sign language. The child also needs regular contact with other adults. The parents therefore apply for a personal home care assistant from the municipality. ***C*** is granted a personal home care assistant four hours a week and one weekend a month.

There are no other children with hearing impairment in ***C's*** kindergarten. Two other children in the municipality are suffering from hearing impairment, but less severe. None of the others will be in need of sign language. It is thus important for ***C*** to meet other children who are using sign language.

The parents also need to meet other parents in the same situation, receive information about their child's impairment and discuss common problems. They are offered the opportunity to spend, with the child, two weeks in the spring and two weeks in autumn in the kindergarten for hearing impaired children. The kindergarten is affiliated to the County Hospital. The purpose is to assemble the staff, teaching them what is entailed in working with a hearing impaired child. They are also offered to attend a course in sign language. These professionals are to visit ***C*** in the kindergarten. They will inform the personnel and the children's group, the health visitor and other professionals in the PP service. Travel and subsistence are covered according to the National Insurance Act.

C's parents need to receive education in sign language. According to the Governmen's Action Plan for disabled people (1994-1997) the Ministry of Church, Education and Research has laid down that parents of children with severe hearing impairments are entitled to forty weeks of training in sign language during the first sixteen years of the child's life. The municipality where the child is resident covers the cost of travel. The national resource centre covers subsistence for the parents, the child and any sisters or brothers of pre-school age.

Based upon the same Action Plan it has been decided that a network course should be held in sign language. The Norwegian Study Association for the Disabled and the Norwegian Association for the Deaf have developed courses for the closest members of the family, neighbours and other people who might be interested.

The family is entitled to standard basic benefit and supplementary benefit. The

family can go to the Social Security Office in the municipality and apply for these benefits. The standard basic benefit shall cover the cost of batteries for hearing aids, extra toys and books the child needs. If the family can document costs of more than 5760 Norwegian kroner (692 Ecus) per year, they are granted standard basic benefit corresponding to this sum.

The supplementary benefit is intended to be a compensation for the extra amount of work having a hearing impaired child involves. A child with severe hearing impairment usually receives standard basic benefit of at least rate 1, that is 10308 Norwegian kroner (1237 ECUS) per year.

Follow-up
There is often a group responsible for the child. The group in charge of ***C*** consists of the parents, the county education officer for the deaf, a teacher from the nursery school at the PP Service centre, a nursery school teacher, the assistant in the kindergarten and a social graduate worker from the Social Welfare Office.

Preparation and organisation of the first days at school, when ***C*** will be six years old, are the most important task of this group. The preparation will begin when the child is about five years old. The different services will have approximately one year to work out and implement plans for making acoustic adjustments to premises, as well as the preparation and training of staff. Instruction in sign language, organisation of an individual teaching plan and pedagogical adaptation of school and extra-curricular activities will be given due considerations.

Case study C (2): a four year old child with severe hearing impairment

Family situation
C lives in Spain in a middle class family, the last of two children. The oldest child presents a deep bilateral neurosensory acoustic loss of unknown origin. There is no family history of deafness from either parent.

The father works as an electrician in a steel factory, the mother works at home. The cultural level of the couple is middle range, but because of the problems presented by their children, they are very interested in the study of the questions linked to this problem area. They give time to the relevant meetings and in spite of the

impact caused by the deafness of their children, the relationship between the couple is good and the family atmosphere is normal.

Child situation

An audiology investigation was completed in the fifth month, by means of Auditory Evoked Potentials at level of the cerebral trunk. ***C*** presents a very deep acoustic loss syndrome at the bilateral-neurosensory level, of unknown origin.

Audiological aids are placed and adjusted in order to work as early as possible with the residual hearing capacities with support from lip reading.

An evaluation of both ears is conducted by the Earphones Adaptation Centre: the right and the left ears receive (respectively) 45dB and 50 dB on average. The bilateral hearing loss is of 80 DB. The child can perceive a range of speech acoustics components, although he/she requires the support of the lip reading in order to facilitate discrimination.

Organisation of early intervention

As of 3 months old, ***C*** has attended a private establishment, subsidised by the State which specialises in language disabilities and especially in treatment through the use of Alternative Communication Systems. ***C's*** brother also attended the same centre. The child was recognised by the IMSERSO (Social Ministry) as having a severe bilateral acoustic loss and has a right to financial support.

The child was brought by his/her own parents to the Early Intervention Centre, as they knew the centre because of their older child. Thanks to this knowledge, the advice to the family has been easier. The initial examination there showed an evolutional development within the normal parameters. The Early Intervention team is responsible for the co-ordination of the support measures needed.

Support

The private establishment supports the child with speech therapy at an individual level, for sessions of 45 minutes, three times a week. In addition there is early stimulation work for one hour, twice a week. This work is conducted within a small group, in order to put into practice the relational aspects of the speech therapy. All the support provided is free of charge.

C joined the Infant school at one year of age, receiving support in the following areas: intervention at a classroom level, for one hour, two times a week, by means of play activities facilitating the aquisition of symbolic play; a co-ordination meeting every three months with the private centre specialised in language disabilities. The child will follow the last year in the infant school. Adaptations for access to the study programme have been implemented.

The Early Intervention team has been present in the speech therapy sessions carried out in the private centre, in order to learn the basic vocabulary associated with the Bimodal System of Alternative Communication developed with the child and also being used at home.

Meetings with the tutor were held during the year, once a week, as well as Bimodal Language sessions with the staff, the aim being for the school staff to learn the same signs as well as new ones, as the child's vocabulary has developed quickly. Meetings with the parents have been held once a trimester.

At present, advances in the level of lip reading and with respect to the number of words the child uses are being noted. The aim of the speech therapist is to focus upon phonetic correction, as well as to continue increasing the child's vocabulary.

Follow-up

The child is very autonomous, without any problem at a daily level. ***C*** is fully adapted to the group. The child establishes a rather good communication relationship with schoolmates by means of faces, signs and through physical contact. There are some children who have learned spontaneously the various signs, facilitating the interaction.

Communication is present in all the activities initiated and developed by the child. This shows there are no problems related to comprehension of verbal messages, when these are adequately said, taking into account the sensory disability.

The parents have raised the issue that their child will eventually leave the infant school and continue in a public school which integrates deaf children.

Appendix 3

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European Agency for Development in Special Needs Education

This book provides a comprehensive overview of Early Intervention services for children with special educational needs in 17 European countries: fifteen European Union Member States plus Norway and Iceland.

It examines the organisation and financing of services and considers the different types of support available in each of the countries. It describes the composition and functions of the teams responsible for early intervention, the participation of families, and the relationship between the education sector and early intervention services.

Current developments and areas of concern across Europe are clearly identified and general findings are supplemented by the use of examples and genuine case studies detailing how particular scenarios for early intervention would be handled in the different countries.

Drawing upon national and international data, this book offers a key source of information not only for policy makers responsible for early intervention services, but also for practitioners and parents.

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